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Issue XXIX

CARF Communiqué

Thank You, Dr. Nicole Rogers

A big thank you to Dr. Nicole Rogers for serving as the physician editor of the CARF newsletter. We really appreciate all you have done for CARE, Nicole!

A little bit about Dr. Rogers, if you didn't already know...

Dr. Rogers is an accomplished hair transplant surgeon and board-certified dermatologist. She graduated with honors from Harvard University and received her medical degree and completed her residency training in dermatology at Tulane Medical School. She also completed a fellowship in hair transplantation under the direction of New York-based Dr. Marc Avram.

Dr. Rogers is co-editor of the textbook "Hair Transplantation." She is an active member of the clinical faculty at Tulane University in the department of dermatology and an active member of numerous societies. When asked how she became interested in hair loss diseases, Dr. Rogers replied:

"I got interested in hair after seeing a hair transplant surgery in Toronto just after college. Years later, I attended a lecture by Dr. Marc Avram on hair transplantation. I went up to him after the lecture and asked him how I could learn to do what he was doing ... I was his first fellow and since then he has had two more fellows. Marc has been a great mentor and we have since published two textbooks together on hair transplantation. He came to visit me at my office last spring and we did a hair surgery together. I love being a hair transplant surgeon and helping people with hair loss disorders."



Dr. Nicole Rogers, Dermatologist in Metairie, LA

Meet Your New Physician Editor—Adriana Schmidt, MD

I would like to introduce myself as the new physician editor of the CARF newsletter. I am a dermatologist in Santa Monica, California, and became interested in hair loss when I was a medical student. My mentor, Dr. Lloyd King, encouraged me to become involved with a support group in Nashville for patients with alopecia areata. This experience led me to recognize the importance of compassion and understanding on the part of health care providers when treating people with hair loss diseases. Dr. Vera Price asked me to lead the CARF group in Southern California when I moved back to Los Angeles in 2010 and I happily accepted. Nicole and I will continue to work together as part of a team of researchers, doctors, fundraisers, donors, and patients who hope to make great strides in our understanding of CICAL!



Drs. Adriana Schmidt and Nicole Rogers

CARF Needs You!

We are here FOR YOU and BECAUSE of YOU. We can do so much for cicatricial alopecia patients around the world because of your support of CARF.

Please consider making a year-end donation to CARF so we can continue to advance our mission in 2016. Every gift matters, especially yours, as we work every day to provide patients emotional support and educational opportunities, raise public awareness and advance and promote research of the cicatricial alopecias.

It's easy to make a tax deductible donation by year's end: <http://www.carfintl.org/donations.php>.

Thank you for your support. Together, we're able to do so much more!

www.CARFintl.org

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Skin Advocate

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

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CARF Physician Referral List— Online for CARF Subscribers

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

CARF Subscriber Database

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

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.

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

Mission Statement:

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

Vision:

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



C . A . R . F .

On fire for research and a cure!

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SUPPORT GROUP NEWS

Report from San Francisco

By Marilyn Ey (Patient Support Group Leader)

CARF volunteers were welcomed at our October meeting: Nancy, CARF's Patient Outreach Volunteer (POV), and Lori, the leader of the newly formed Pittsburgh Support Group. Nancy corresponds with the newly diagnosed and anyone wishing to learn more about CICAL. Lori shared a presentation on "JOY," an acronym for Judgment, Options, and You. For "Judgment" she encouraged us to think positively instead of negatively about ourselves. Lori's photo of a kitten looking in a mirror and seeing a lion really made her point hit home. In the "Options" portion, she challenged us to explore different pathways to find those that lead us to a better place. Options include wigs, hairpieces, cosmetics, medical treatment, making friendships, and other camouflaging techniques. In "You," Lori made us realize that making ourselves miserable takes just as much effort as making ourselves strong. So think how you can find JOY in your CICAL (Cicatricial Alopecia) journey.

Support Group Meetings allow for the sharing of ideas, information, tips & tricks, answers to patient questions, camaraderie, a place to laugh, and a place to cry. Here are excerpts from recent discussions:

- UCSF Department of Dermatology offers a Hair Disorder Clinic the 2nd and 4th Friday afternoons of each month. Though Dr. Vera Price has retired, she still participates in these events with other notable medical experts.
- Is CICAL an autoimmune disease? CICAL does not involve specific antibodies nor is CICAL typically found in families. Both of those are requirements for autoimmune classification. Unfortunately, CICAL can reactivate after years of inactivity. Face lifts and hair transplants can cause CICAL to flare up. Currently, hair transplants are not an option for CICAL that is still active.
- Several patients use the term "burn out" to mean not having any symptoms accompanied by no hair loss. Many terms doctors and patients use are confusing.
- Basic clarification: FFA, CCCA, and LPP are NOT different diseases nor are they different forms of CICAL. They all fall into the "lymphocytic" category of CICAL and appear as lichen planopilaris under the microscope. We use FFA (Frontal Fibrosing Alopecia) to describe hair loss usually at the forehead, around the ears, and at the nap of the neck. CCCA (Central Centrifugal Cicatricial Alopecia) describes hair loss located at the top of the head. LPP (Lichen Planopilarus) is used to describe any other lymphocytic hair loss location. Under the microscope science cannot distinguish FFA from CCCA.
- It is important to educate yourself about exactly what you need before spending money on hair options. The last thing you want is to hide a \$1,500 wig in a closet because it wasn't best suited for your needs.
- One patient shared how important it is to quit anticipating hair loss. Worrying about future hair loss can just make you miserable.
- One gentleman used scalp hair fibers (Eclipse, Toppik) to improve his appearance in wedding photos.
- Depending on the location of hair loss, consider using different hair systems for different levels of activity. For vigorous exercising, avoid rubber or synthetic-based hairpieces and wigs. They cause sweating, which increases hair follicle inflammation. Instead use those pieces made with breathable mesh backings. For swimming, wear a "nammu cap" (found at nammu.com or on Amazon.com). While lounging poolside, walking, hiking, or gardening, wear a large-brim hat with drawcord for wind. Google Columbia hats, which are available at REI or through Amazon.
- To reduce itching and burning, place a bag of frozen peas on the affected areas of your scalp. Shampoo and rinse with cold water. Also avoid hot setting on hair dryers. Remember: heat is bad, cold is good when addressing inflammation.
- An "integrated hair system" can be secured using clips, tape, and hair. An integrated hair system is specifically designed hole placements that allow hairs to be pulled through for added security. Make headbands (the funkier the better) using left over material. Can't sew? Purchase headbands online or at stores (REI, Amazon). When spending the night with friends or family, a headband is a comfortable and attractive concealment solution. One lady wears a stretchable wool buff over her integrated hair system. Sometimes she wears a "Brett Michael" style bandana for a kickback look.
- Another attendee shared how eyebrow permanent makeup (aka tattoo) simplifies her life. It eliminates drawing eyebrows on every day and worrying about accidentally rubbing them off. Permanent eyebrow makeup also allows you to swim with confidence.
- One husband shared how his wife is the strongest person he knows. She doesn't give up battling FFA. He recommends doing what she does: Search for medical and cosmetic options until you find whatever works for you.
- Another member shared how hair loss causes patients to "re-grieve" the five stages of grief (denial, anger, bargaining, depression, acceptance). Just about the time a patient finally accepts his/her condition, "CICAL HAPPENS." Then CICAL starts that emotional roller coaster ride all over again.

Many in our group have attended a CARF Patient-Doctor Conference. Expect medical, emotional, and camouflaging information along with having lots of fun while making new friends. New conference attendees are surprised by how everyone's hair looks normal. You'd think you were at a PTA meeting! For a life-changing experience, attend the June 3-5, 2016, New Orleans Conference. Stay over Sunday night and plan and attend an afternoon get together in the hotel's breakfast room. There you'll relax and bond with your "Cicatricial Cousins" in our CICAL "Follicle Family."

Hope to see you there!

FREE WIG: The Wig Source at John Muir Medical Center, Walnut Creek Auxiliary in California offers free wigs to anyone with any form of alopecia. Make an appointment by calling 1-925-947-5328. Appointments are the 2nd and 4th Fridays of the month, 9:30AM-12:30PM. Not in the San Francisco area? Go online to see what opportunities are located in a city near you.

SUPPORT GROUP NEWS

Report from Pittsburg, PA

The inaugural Pittsburg support group was held on August 27, 2015. The meeting was hosted by support group leader, Lori Bertella, who kicked off the meeting with a presentation about perspective and attitude. Next was an open Q&A session with Dr. Joseph English, which turned out to be very informative and helpful to the attendees. We also had a local hair replacement specialist, Debbie Mancuso, owner of Hair Replacements of Pittsburg, in attendance. Debbie was kind enough to bring a number of displays and discuss openly how many options women have based on the degree and type of hair loss. This presentation helped set some minds “at ease,” knowing that there ARE options for us all! We closed the evening with a moving PowerPoint presentation filled with everyday reminders about our approach to not just hair loss, but to any change we may be going through. All in all, it was a very successful meeting, and we hope to continue to grow participation and strengthen the support network to the Pittsburg and surrounding areas.

Report from South Louisiana

By patient Elayne Kuhler

We had a nice turnout for our CARF South Louisiana Group. We had a member come all the way from Atlanta, GA, and it was so exciting to meet her! Welcome Sue French. We did miss Dr. Rogers, who had other obligations, at our meeting on Sunday, but we did very much enjoy meeting Dr. Andrea Murina.

We were also so thrilled to meet Ellen Cortello, our program director. Ellen is a cancer survivor and lost her hair due to chemo. The good news is that she is cancer-free today and her hair did grow back. She is here to encourage us by sharing her personal story and by complimenting all of us on how great we all looked. She explained how hair is not as important as caring and understanding. Throughout her illness due to chemo, she motivated herself by getting up every day and getting dressed and putting her makeup on. She did use a scarf mostly when going out, which made for a very attractive look. She brought her brochure, “ChemoPerfect.” Her website address is www.chemoperfect.com. Here, you will find advice on how to tie scarves, apply false eyelashes, stencil on your eyebrows, and select the perfect earrings to make your look complete. You may also get in touch with Ellen through email at info@chemoperfect.com or by phone at 1-504-201-1020. She is located in Metairie, LA. Her motto is Stay Strong... Stay Positive.



Members of South Louisiana support group

Ellen drew names and gave out about 6 gifts of either scarves or earrings. That was so special and fun!

I am sure I speak for all of us at the meeting when I say that we all very much enjoyed Ellen’s program as well as seeing and talking with each other and feeling the support from of each of us there.

We sure hope to see everyone at our next meeting in January.

Additional notes from Dr. Andrea Murina on New Orleans, LA, meeting:

At this meeting, we were introduced to Ellen Cortello, who is the founder of ChemoPerfect, a retail and consulting company that helps patients undergoing chemotherapy look and feel their best. Ellen has a very positive message about not being ashamed of hair loss associated with illness, whether cancer or a scarring alopecia. She underwent cancer chemotherapy for transitional cell carcinoma and lost all of her hair for about a year. During that time, she described her daily anxieties about her health and her appearance. Just when she was about to lose her last bit of normal hair, she recounts the feeling of release and calm after shaving her head for the first time.

Members of the group shared their stories about their life with Lichen Planopilaris and Frontal Fibrosing Alopecia. They pointed out that their disease is a chronic struggle and unlikely to be reversible like the Anagen Effluvium that occurs with chemotherapy. Specifically, their concerns are that their alopecia would be revealed in a public setting.

Ellen had an interesting spin on this concern. She focused on the liberation that occurs after exposure of the real you. Ellen wants women to allow themselves a little freedom from wigs whenever possible, and allow some people to know about their disease. Instead of being set on always covering up and hiding the alopecia, we can use scarves, hats, and other head coverings when at home and around loved ones. ChemoPerfect sells a headscarf that is soft and easy to wear. Wearing a headscarf may draw more attention but Ellen emphasizes that doing this can help with self-acceptance. As the saying goes, “Change your mind, change your life,” but wearing a headscarf could possibly be a way to change your mind about alopecia. Ellen encouraged the CARF members to reveal more of themselves and be a little bit freer to live life as they want to live it. Ellen also encouraged the members to highlight their facial assets by wearing makeup, false eyelashes, and earrings in order to highlighting the positive. She believes that putting effort into looking our best will help us to feel our best.

The members of CARF are already an amazing and attractive group. Their sincerity and honesty about the impact of their disease is touching. There are more questions than answers about Cicatricial Alopecia, and so dealing with uncertainty is part of our members’ daily lives. Having a sense of control about the way we look is key to feeling more confident, and Ellen gave inspiration for more self-acceptance and positivity.

PATIENT CORNER

Tips from a FFA/LPP “Cover” Girl

By Curle Temple, California

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

Did I “need” a hairpiece?

I have had thinning hair since my mid-40s and always tried to disguise my scalp with comb-overs. When I was diagnosed in 2014 with FFA, LPP, and Androgenetic Alopecia, my hair’s future looked dim. I imagined 3 states of being: 1) loss of well-being; 2) coping (meds, support groups), and 3) forgetting about “it.”

My loss was moderate and some would say I looked “okay” without a hair addition... “A lot of women have thin hair...” or “You look nice in a headband.” It’s how we feel about ourselves that matters, though, and I knew that finding a viable lasting way to disguise my loss would make it much easier for me to accept CICAL and its unknown progression. I want to stay in the “Forget about it” state as much as possible.

Finding a Solution

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

Are you ready to explore solutions for yourself?

Acknowledging that a hair addition might be part of your life is a big step, so be patient and methodical, and, most of all, have compassion for yourself even if ultimately you decide not pursue getting one.

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

Resources

Alopeciaworld.com

Wigsupport.com

Womenshairlossproject.com

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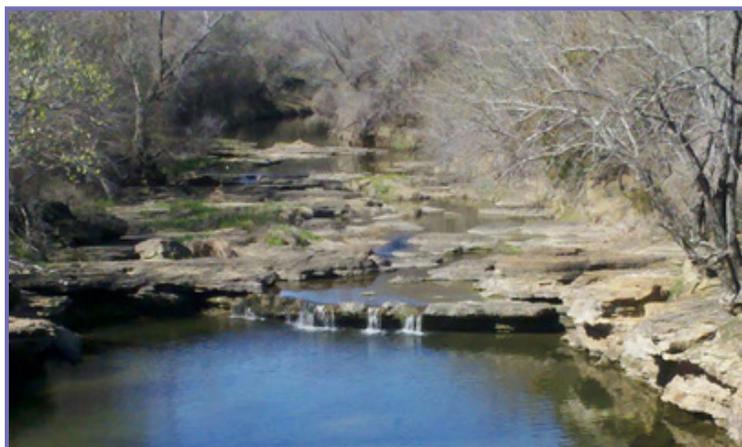
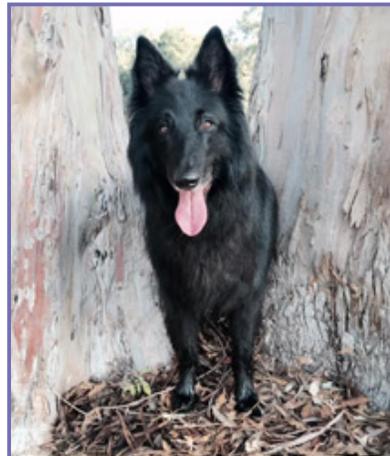
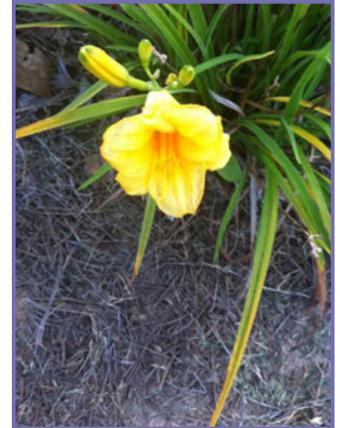
Slow Stroll

By Marilyn Ey

The best Cicatricial Alopecia (CICAL) advice I ever received was at a support group meeting. Dr. Vera Price said, "Stress doesn't help any disease." Did I immediately heed her advice? Unfortunately, I did not. It took two major CICAL "flare-ups" for me to realize **CICAL LOVES STRESS!** So I decided to "UNFRIEND" stress.

My first stress reduction training day was similar to starting a diet. I knew I'd slip up but eventually reach my goal. It took months and months for "this old dog to learn new stress-reducing tricks." Eventually, I taught myself how to change my attitude, reduce stress, and become much calmer. A weekly "slow stroll" was one of the ways I accomplished my goal. Maybe a slow stroll will help you reduce stress. Just try it once and see how much better you feel. Then repeat!

For an hour, slowly stroll through a beautiful setting...alone. During your stroll, take numerous photos of the colors and textures in nature. Photograph puffy white clouds in the sky, a stream flowing through rocks or boulders, the different barks of trees, a bee buzzing, a flower, a sunset, a tree-lined road, animals, fence posts, rustic siding, or whatever you see that captures your eye. Focus on framing each photo and take several shots. Stroll a little further and continue capturing nature's beauty. After your stroll, review all photos and delete all, but your favorites. Congratulations! You've just given yourself a mini stress-free vacation and it didn't cost a penny!



Photos taken by Kathryn Hill, T.A.P., in Atlanta, GA, and Marilyn Ey.

PATIENT CORNER

My Hair “Peace”

By Sista T

In February 2014, I was diagnosed with Cicatricial Alopecia (both FFA & LPP). In addition to the devastating diagnosis, I had suffered from an allergic reaction to hair dye. I am still dealing with the side effects of being poisoned by hair dye. My third challenge was that most manufacturers don't produce silver/white/gray wigs or hairpieces. Most women prefer any color other than their natural hair color. I understand completely. I finally bought a hairpiece in hopes of covering up my frontal loss and thinning of my bangs. I needed something that would create a fuller look.

The hair clips on the hairpiece were my fourth challenge. They caused itching and discomfort on both sides of my head. I immediately removed the hair clips from the hairpiece, and sewed my hairpiece on a very narrow elastic band. I purchased the elastic band at a fabric shop. I believe it's crucial that the band fits well. It's important to purchase different sizes and experiment wearing the elastic band before sewing it on the hair piece. Comfort is crucial when it comes to our hair disorder. Too tight doesn't work on our sensitive scalps. I have experienced that the less our scalp is irritated, the better our scalp feels.

I wash my hairpiece and elastic band as needed. I use a Styrofoam head to sustain and store my hairpiece. When I'm ready to go out, I put on the hairpiece, combine my own hair with the hairpiece by combing them gently together and using hair spray to keep them in place. I either put a headband, a scarf, or my hat over my hairpiece. I'm ready to go!

It's been so much fun wearing different scarves and headbands (dressing up or for working out), and I'm in love with my hats. I feel empowered. I enjoy having options and I'm told I look like a Fashionista without a care in the world. I love my hairpiece because it's quick and user-friendly. I never had so many options before my diagnosis. There is a silver lining for me (pun intended); maybe there is one for us all?

When I'm home, I don't wear the headbands or hats. When I'm out in public for short periods of time, I often wear my headbands without the hairpiece. Wearing my headband a little lower on my bangs keeps them from lifting up and showing my loss. It's a great solution for casual situations.

I love my hats and they are now my new BFFs. I now have another addiction (besides my jewelry): my hats. When there's wind, rain, and or humidity, I wear my hat. Once I arrive at my destination and my hat isn't acceptable, I have my “go to bag of hair tricks.” I go into the ladies room and blow out my hair or use a flat iron on my bangs. I put on one of my headbands and off I go to enjoy my evening, dinner, or work meeting.

I constantly receive compliments about my choices in headbands and hats! It brings me such joy and puts the biggest smile on my face. No one knows what I'm dealing with under my hairpiece. Better yet, my hair loss doesn't identify me or control my life. I don't want it to be my story or define me. It's very empowering when I find alternative ways to look great. I'm my new normal and loving every minute of it.

I have created a piece for my peace.

Questions about my hairpiece, contact me at tas8286@yahoo.com.



My scalp with FFA hair loss.



My hairpiece on with another headband covering it up and my hair in an updo.



My hairpiece on with a hat. I have ten more hat choices.

PATIENT CORNER

Cicatricial Sisters Share

The following is from the hearts of six Cicatricial Alopecia (CICAL) ladies. Originally they called themselves “Cicatricial Sisters,” changed it to “Sistatricals” (sisters with cicatricial) and now “Sistas.”

“Sista JK” Shares

I have hidden this disease for years and years. I never really reached out to investigate options because I was successful just “hiding.” My internet searches never revealed anything useful until I found the CARF website. The descriptions and the pictures...it was ME. Through CARF, I was put in touch with another member, and for the first time ever I was talking to someone on the phone...like ME. She had the same issues, same fears, and same frustrations. It was life-changing to know that another living, breathing person shared my isolation.

I continue to successfully hide my loss, even from my closest friends and family. Hiding is exhausting, though. Being able to talk about it freely in front of fellow patients at the CARF Patient-Doctor Conference in Chicago (2014) was the most liberating experience. I didn't have to lie! I didn't have to pretend! Everyone else was equally concerned about the wind of the Windy City—and for the same reasons as me!

My Cicatricial Sistas provide that same feeling. I met most of them at the Chicago Conference. They were the best souvenir ever. Knowing someone else is going through the same thing is absolutely priceless. They provide information, creative camouflaging ideas, humor, and attitude adjustments when needed. One simple cry for help is met with thunderous support and encouragement. My Sistas are my Support.



Wyoming Sista Shares

The five years between losing a few eyebrows and having a very small spot of hair loss above my forehead to losing all eyebrows and more hair and getting the diagnosis (biopsy) is pretty much a blur. As a private person, I just carried my own burden of losing hair and eyebrows that will never return. Support groups were not for me (none available anyway). However, when the Chicago CARF Doctor-Patient conference was being planned, a woman from California with the same diagnosis as mine (FFA) encouraged me to attend. The conference was amazing with 124 patients attending. All had the same diagnosis as me—scarring alopecia—and they all looked “normal”!! Along with the lady from California, I met four other wonderful women. When we returned home, we kept in touch via email. These women became the support group that I thought I didn't need. We eventually added a sixth person and called ourselves the Cicatricial Sistas. Fast forward: I now am a CARF Patient Outreach Volunteer (POV) and have the opportunity to support others.

Another CARF Patient-Doctor Conference will be held in New Orleans the summer of 2016. My wish is that everyone finds their Cicatricial Sista (or Brotha) in New Orleans.

“Sista Tamara” shares

I was diagnosed with Cicatricial Alopecia in February 2014. My diagnosis was devastating. In addition to the diagnosis, the dermatologist had no idea how to support me. Within five minutes of the diagnosis, I was standing out in the parking lot feeling completely blindsided, confused, and in complete shock. I'm not sure if the feeling of being alone was actually worse than the diagnosis itself.

After many hours of crying, feeling alone, and online research, I found CARF. I contacted them immediately, and they put me in touch with a CARF POV (Patient Outreach Volunteer). When she called me, I was beyond excited to learn there was someone else out there. My hopelessness began to soften; my new found friend was a “life raft” off the lonely, strange island called Cicatricial Alopecia.

In addition to speaking with this marvelous lady, I signed up to attend the Chicago Patient-Doctor Conference. I had no idea what to expect, except I was determined to understand this disorder and find a solution. The conference gave me hope, treatment choices, and new friends! We all bonded immediately, and now have our own virtual support group.

I'm no longer floating in deep open scary waters, or stuck on the lonely island. I gained a powerful “life raft” called friends. My new friendships have offered me a unique community of hope, support, kindness, and empathy, and a powerful journey called “Sisterhood.” I'm a much better person because of my sistas.

“Little Sista” Shares

For five years, I lost hair. For the most part, I ignored it because I could mask it with existing hair. In December 2014, I finally asked my dermatologist if it was ever going to “come back” (I was misdiagnosed with Alopecia Areata years earlier). The dermatologist said a biopsy was needed because it might be “scarring alopecia.” I had no idea what that was, but it didn't sound good. Fast forward a couple of weeks and two biopsy punches later: It was FFA. I was in a bit of a tailspin, and spent countless hours on the internet looking for hope. That hope did not come from a website or blog. That hope came from a phone call and email from a woman who genuinely cares about this disease, and who sincerely wants to help women (and men) who are walking (sometimes crawling) through this journey. She then brought me into a circle of women who were equally as passionate and equally craving

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PATIENT CORNER



knowledge about FFA. And that is exactly what we've done for the past eight months or so. We share knowledge. We also share successes, family events, hard days, happy days, concealing techniques that put Harry Houdini to shame, and, most importantly, we share a common bond and friendship. These five women helped boost my confidence. They've helped me get an emotional grip on this disease and made me see that when that grip loosens that it is OKAY. They show me love every day in the form of a kind word, a heartfelt message, or a tremendous sense of humor. I saw this quote a few weeks back. To a large degree it sums up my amazing relationship with these fine women:

When "i" is replaced by "we," even "illness" becomes "wellness." (author unknown)

"Sista D" Shares

I was stunned when I was first diagnosed with FFA/LPP in February 2014. Living with this difficult-to-treat, progressive disease with uncertain medical outcomes surely is difficult no matter if it is not life-threatening. However, it is life changing.

Having a rare condition is lonely. The emotional aspects of this disease cannot be underestimated. Losing hair felt like my identity was being erased. The hardest part is acceptance. I grieved the loss and then I accepted. I lose more hair and go through the cycle once again as I redefine and move forward with my life.

Fortunately, I found out about CARF early on and went to the 2014 Chicago Patient-Doctor Conference. Meeting other patients was the most invaluable part. I found sharing tips, nuances, vulnerabilities, and coping methods only another CICAL would know was surprisingly bonding and healing. I've learned that giving support gives back. It has made a huge difference in my ability to put this disease in its non-life-threatening perspective, get beyond the emotional paralysis, and take control of my life.

"Sista ME" Shares

Since being diagnosed eight years ago, I've attended CARF-supported Patient-Doctor Conferences and numerous support group meetings. Along the way, I've made many CICAL friends. When our "sistahood" emails began, I had no idea how much I would cherish these wonderful ladies. Since I have emotionally dealt with CICAL, I expected to be the "mom" of the group. Just like any family situation, sometimes "mom" also needs help. This happened when I experienced a new health issue. Was I scared? You bet. When I shared my fears with my sistas, I immediately received overwhelming love and support. Despite feeling frightened out of my mind, their emails provided a much needed calming effect. Each email felt like a big hug. In trying to mentally adjust to my new health problem, Sista "JK" wrote an encouraging, "You got this." Those were the perfect words I needed to hear. Those were the words I clung to when terrifying thoughts entered my head. Although I'm not 100% yet, I have confidence that "I got this." More importantly, "I got my sistas."

Support group meetings and Patient-Doctor Conferences are ways to meet others who truly understand CICAL's emotional "roller coaster." My CICAL friends and sistas make my CICAL "ride" so much more enjoyable. The CICAL journey is much easier when shared. We are all part of the "Cicatrical Family." Maybe we can meet YOU, our "Cicatrical Cousins," at support meetings or at the New Orleans Conference.

PATIENT CORNER

CARF Conferences May Be “Game Changers”

By Susan Huffman

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. 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 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.

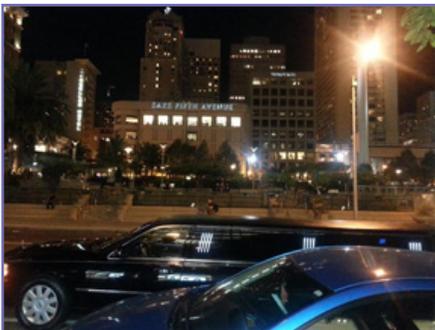
Just a week before my FFA diagnosis I had been diagnosed with breast cancer. Needless to say, I was a little overwhelmed at that point. Once I got through my surgery and treatment for breast cancer, I focused on the FFA. I switched dermatology practices and found a doctor who had much more empathy for 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 Patient-Doctor Conference in Chicago.

The Chicago 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 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 research of Cicatricial Alopecias. The prize for the raffle was a trip to San Francisco, CA, or Key West, FL, and it was made possible by the generous donations of hotel points and air miles by Mr. Laurence Spector and Dr. Ken Washenik. My husband and I were lucky enough to win this raffle and had a wonderful trip to San Francisco in October 2014 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 raising funds with the raffle to help find treatments and cures for Cicatricial Alopecia.



If you are coping with a Cicatricial Alopecia, consider attending the 2016 CARF Patient-Doctor Conference in New Orleans. The information and support you will receive there can be as great 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.

PATIENT CORNER

Turning Loss into Growth

By Amanda Kleinman, MD

As Heraclitus noted in the year 500 BCE, “Everything changes and nothing stands still,” or otherwise worded: The only constant in life is change. By its very nature, change means new things coming into our life and old things departing. The arrival of new things can feel enjoyable, like a good conversation with a new friend, or feel uncomfortable, like a new sound coming from the car engine. The loss of old things can feel sad, like outgrown baby shoes, or feel relieving, like sending in a final mortgage payment.

The process of aging is arguably one in which the body is in a state of steady, progressive loss. The illness of Cicatricial Alopecia would seem to sharpen a fine point on this process of loss. While age changes everyone’s appearance, this illness forces an irreparable change to a vital component of one’s social identity, and does so at a rate that is much faster than other elements of one’s expected decline.

As illness changes the body, one might encounter subtle changes to one’s relationships due to subtle misunderstandings. One might also encounter changes to one’s interpersonal roles, such as becoming “the sick family member.” These changes can incur a constant, negative stress that can feel overwhelming at best and leave a person feeling powerless and hopeless at worst.

So how can we restore our life’s balance in the face of progressive loss? How can we turn our position into one of incremental gain where the “goods” outnumber the “bads”?



Amanda Kleinman, MD



wake up each day. It should be engaging, fun, creative, and above all satisfying.

A final way to tend to ourselves is to keep good people in our lives. This means reaching out to meet new people and always being open to expanding one’s personal community. It means engaging people who have shared a spark of mutual interest and finding ways to deepen the acquaintance to a more meaningful friendship. It means spending less time interacting with and thinking about people who bring little support or joy to our lives—even if the transition is difficult at first.

As we refocus our efforts towards activities that are helpful and positive, we can begin to enjoy more balance and greater emotional resilience. We can restore some element of control in our lives, readjust our personal goals accordingly, and rekindle a newfound sense of hope—hope that our time on this earth will show a garden that is beautiful, lush, and well-tended.

One way is to become assertive about creating and enhancing the good things in one’s life. As in gardening, we can’t control how the elements will affect our plants, but we can control how we tend to them.

Tending to ourselves starts with caring for our bodies and minds. This means choosing good and wholesome food to eat and getting regular physical exercise so that the body can be as healthy as possible, even in the face of illness. It means seeking out counseling to work through grief, giving voice to unspoken suffering, and opening the mind to more open, honest, and healthier perspectives. It may also mean pursuing spiritual guidance in order to relinquish one’s mortal sense of control and open the heart to a deeper awareness and acceptance.

Tending to ourselves also means giving ourselves good work to do. This might mean a long-delayed career change, more time volunteering for a meaningful organization, or taking time to explore a hobby that has long sat neglected. Good work organizes our time, gives structure to our goals, and provides a reason to



ABOUT DR. AMANDA KLEINMAN

Dr. Amanda S. Kleinman is an assistant professor of Psychiatry and Dermatology at Rush University Medical Center in Chicago, Illinois. Dr. Kleinman attended medical school at Northwestern University in Chicago and completed a psychiatry residency at the University of Washington in Seattle. Dr. Kleinman joined Rush in 2007 as the Director of Outpatient Psychiatry, overseeing growth and development of the central outpatient clinic and transforming resident education in the outpatient setting. Dr. Kleinman additionally has served as an Assistant Program Director for the Psychiatry Residency at Rush University. Dr. Kleinman entered the field of Psychodermatology in 2009, partnering with Dermatologists Dr. Michael Tharp of Rush University and Dr. Warren Piette of John H. Stroger Jr. Hospital of Cook County. Special areas of interest include hair loss, unresolvable itch and delusions of parasitosis. Dr. Kleinman entered private practice in July 2014, practicing general psychiatry and psychodermatology.

MEETINGS, ADVOCACY & AWARENESS

AADA 2015 Legislative Conference September 29, 2015 • Washington, DC

By Rita Wanser, CARF Chairman of the Board

I represented CARF at the annual Coalition of Skin Disease (CSD) Development Day. The Coalition is an advocacy group that speaks with one voice for skin diseases. We are one of approximately 16 other patient advocacy groups to be a part of this collective organization. Each year, members of the coalition get together with members of the American Academy of Dermatology Patient Advocacy team to discuss how the AAD can help support our collective advocacy efforts to dermatologists, patients, and public education on skin diseases.

This year, we heard three presentations. One was on fundraising, another on patient registries, and a third presentation was given by one of the coalition members on how they certify their patient coaches to ensure a high level of interactions with their patients. While we do not have a formalized “certification,” I was happy to hear that we have many of the same principles in place on how we prepare our volunteers for patient queries and concerns as they struggle or learn about their hair loss conditions.

We were also joined by our AAD representatives, and the current president of the AAD. While we have always had supporters from the AAD, this year’s president, Dr. Mark Lebwohl, is a staunch leader for patient advocacy and has been quite active with the CSD and moving projects along. The Patient Advocacy Task Force is quite active, meeting regularly to brainstorm on efforts for creating awareness of our patient groups to dermatologists and advance our education efforts. The patient advocacy groups are experiencing a very exciting time with our interactions with these key leaders at the AAD. Stay tuned for progress updates.

The Development Day meeting always precedes the annual AADA Legislative Conference. The Coalition partners with dermatologists, residents, patient advocates, and representatives from the Associate of Dermatology Managers/Administrators and Dermatology Nurses Association to meet with members of Congress and House of Representatives on Capitol Hill to voice the concerns over the issues facing dermatologists’ ability to practice, which in turn may affect our ability as patients to receive dermatological care. We met with legislators in both the House and Senate. Notably, 75 of the meetings were with “targeted” offices, where the members of Congress sit on committees of jurisdiction over key health policy legislation.

This year, the main topics of discussion were to seek support against the narrowing networks within the insurance companies against limited prescribing access and affordability of prescribed medications. Our final “ask” is for increased National Institutes of Health (NIH) funding. Insufficient funding for research not only restricts the availability and amount of funding, but it also deters scientists and physicians from going into research as they cannot continue their work without financial support. For CARE, this can create a huge impact on understanding our conditions and finding treatments.

Besides supporting the dermatologists, these visits also help us to advocate on your behalf. I get to bring to life the emotional impact of Cicatricial Alopecia. Our visits to Capitol Hill put into perspective how neglecting NIH funding as well as making access to treatments and physicians more challenging can negatively impact our patients.

Our legislatures are interested in what their constituents have to say, and bills have passed as a result of these conferences. Patient stories are important to share in order to highlight real people and real impact. Three patients joined the coalition this year on Capitol Hill. I expect that next year more coalition members will be asked to bring patients as well.

CARF will be represented at the National Organization of Rare Diseases conference, which will have occurred by the time you read this. Look for an update on this conference in our next *Communiqué*.



Rita Wanser



MEETINGS, ADVOCACY & AWARENESS

International Society of Hair Restoration Surgery's 23rd Annual Scientific Meeting Sept. 18-21, 2015 • Chicago, Illinois, USA

Victoria Ceh, MPA, CARF Executive Director

At the recent annual scientific meeting of the International Society of Hair Restoration Surgery (ISHRS). Dr. Ricardo Mejia, dermatologist from Jupiter, FL, moderated a session on proper diagnosis of primary Cicatricial Alopecia and the possibility of surgical treatment. Presentations were given by Drs. Ricardo Mejia, Ekrem Civas, and Jeff Donovan. Dr. Donovan reviewed data on hair transplant graft survival in FFA patients; these were results of a 2-year follow-up study. His take-home messages were the following: 1) disease quiescence appears to be a fundamentally important factor in predicting success of hair transplantation for FFA, and 2) graft survival is enhanced with use of bigger grafts, use of concurrent therapy, and selection of patients with minimal atrophy.

The conference included over 1,000 physicians, surgical assistants, researchers, and industry representatives from 58 countries who specialize and/or have an interest in hair loss and hair restoration surgery. Topics ranged from surgical techniques for hair transplantation, medical therapies for Androgenetic Alopecia, and scientific research on hair disease to specialty topics including eyelash and eyebrow transplantation.



Victoria Ceh, MPA



We gratefully acknowledge the ISHRS for the photos.

Coming Down the Pike

Victoria Ceh, MPA, CARF Executive Director

Several important meetings to Cicatricial Alopecia are upcoming and a few are listed here. The 9th World Congress for Hair Research will take place November 18-21, 2015, in Miami, Florida. The Congress is hosted by the North American Hair Research Society and is a global convention with anticipated attendance of 500-600 including hair researchers, clinicians, patient advocates, and industry representatives. The ultimate goal of the Congress is to present new research, share experiences, and discuss new directions for the advancement of knowledge in hair growth, hair and scalp disease, and clinical care.

The topic of Cicatricial Alopecia has its own session with Director Dr. Elise A. Olsen (USA) and Co-Director Dr. Andrew G. Messenger (UK). Invited speaker includes Dr. Nonhlanhla P. Khumalo (South Africa), and several submitted abstracts on the topic will be presented orally. In addition, there will be poster presentations and additional free paper sessions that include Cicatricial Alopecia research. Saturday morning of the Congress will include a small format discussion session. Several table topics have been designated for Cicatricial Alopecia. The meeting provides a stimulating environment for researchers to discuss theories and form collaborations. Additional information on the Congress can be found at www.hair2015.org. Stay-tuned for meeting highlights in the next *Communiqué*.

The CARF Scientific Advisors, under Chairman Dr. John Sundberg, are planning a Cicatricial Alopecia Research Symposium & Roundtable at the 2016 Society for Investigative Dermatology Annual Meeting, taking place May 11-14, 2016, in Scottsdale, AZ. The Symposium will include invited presentations (e.g., what is known about the disease, what are the theories about what is causing the disease, etc.) followed by a closed roundtable discussion session of the CARF Scientific Advisors to chart the course of directed research for the coming year(s).

And, finally, the CARF 7th International Patient-Doctor Conference will take place June 3-5, 2016, in New Orleans, LA. Program Chair Dr. Nicole E. Rogers (USA) is organizing a top-notch program! The Conference occurs every other year and is a "must" for newly diagnosed patients as well as patients who have lived with the condition for many years, and also for physicians who treat Cicatricial Alopecia. The Conference includes many informative lectures to deepen your knowledge about Cicatricial Alopecia. It is a warm and sharing environment. Patients who previously felt alone with this condition receive support and friendship, as well as the realization that they are not alone! Tips and tricks to live positively and with acceptance are discussed. We hope you will consider attending. For more information, go to <http://www.carfintl.org/patient-dcotor-conference.php>.



MEETINGS, ADVOCACY & AWARENESS

Get Jazzed for the next CARF Patient-Doctor Conference!

7th International Patient-Doctor Conference
Hampton Inn & Suites New Orleans Convention Center • New Orleans, LA, USA
Friday-Sunday, June 3-5, 2016
Host: Dr. Nicole Rogers

Registration opens December 2015



The Cicatricial Alopecia Research Foundation (CARF) together with Dr. Nicole Rogers and the CARF South Louisiana Patient Support Group invite you and your family to attend a two-day educational conference. Learn more about the latest in research and treatment options, and network with other patients, loved ones, and physicians.

This CARF biennial conference is a must for patients and physicians involved with cicatricial alopecia. Attendees attest to a life-changing experience after participating in a variety of lectures, discussions, support groups, and more.

Why patients, families, friends, physicians, and nurses should attend:

- Learn more about the diagnosis and available treatments.
- Discover the latest research breakthroughs for cicatricial alopecia.
- Hear about cosmetic solutions.
- Meet leading physicians and researchers in an informal setting.
- Participate in small group discussions, meet new friends and get support.
- Explore the history and culture of New Orleans.

Enjoy all of these important benefits with the soul of New Orleans as the backdrop. Be sure to take time to explore the wide variety of attractions this beautiful city has to offer.

For more information including the full program agenda and to register, please visit:

<http://www.carfintl.org/patient-doctor-conference.php>



*Hampton Inn & Suites
New Orleans Convention Center*

What is a CARF Patient-Doctor Conference?

A CARF Patient-Doctor Conference is a place for patients and doctors to come together in a safe and supportive environment. It's a place where you can learn about cicatricial alopecia and the latest medical research in finding a cure, a place where you can meet others with cicatricial alopecia and share your stories, a place where you can discover products and lifestyle changes to better manage your dis-ease, a place where you will become empowered and given hope, and a place where you can be yourself. Our patient conferences have changed people's lives and we hope they can change yours as well.

Celebrate Rare Disease Day on the Rarest Day of the Year—February 29, 2016

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

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://rare diseaseday.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.

For those who live outside of the United States, please visit <http://www.rare diseaseday.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

CLINICAL TRIALS & RESEARCH STUDIES— RECRUITING PATIENTS

Recruiting Patients for U.S. Frontal Fibrosing Alopecia Study

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

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

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

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

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

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

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

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

University of Miami
Miami, Florida
Investigator: Antonella Tosti, MD
Contact: CKittles@med.miami.edu

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

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

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

RESEARCH FINDINGS

2013 CARF Research Grant Recipient: Helen B. Everts, RD, PhD

Research Study:

“Endogenous Retinoids in the Pathogenesis of Cicatricial Alopecia”

Biography

Dr. Helen B. Everts obtained her bachelor's degree in pre-medicine from the Pennsylvania State University, and her Master's and PhD in nutrition from the University of Georgia. At the University of Georgia, she began her work in the retinoid (vitamin A) field, examining the role of dietary vitamin A in mitochondrial function and gene expression in an animal model of diabetes. She obtained additional experience with retinoids in a postdoctoral fellowship under the mentorship of David E. Ong at the Vanderbilt University Medical Center. Here she met Lloyd E. King, Jr. and John P. Sundberg, who trained her on hair and skin pathology. She then became an Assistant Professor at The Ohio State University in 2008. Her research is focused on understanding vitamin A metabolism in skin and hair during health and disease. Thus far, her studies have focused on understanding retinoid metabolism and function in Cicatricial Alopecia, Alopecia Areata, and skin cancer.



Helen B. Everts, RD, PhD

Background

Studies in mouse models of Cicatricial Alopecia suggest that retinoid metabolism is altered in Cicatricial Alopecia. Several steps are involved in the conversion of the vitamin A that is eaten in your diet to the active form of the vitamin (retinoic acid, RA). The last two steps in this process occur at the site of action. There are also several proteins involved in the action of RA and in degrading RA. Some of these proteins are also regulated directly by RA to maintain homeostasis. In mouse models, many of these proteins and retinoid levels are increased in mild disease, but these proteins become reduced as the disease becomes more severe.

Research

We examined the amount and location of four of these proteins involved in RA synthesis, degradation, and action in skin from patients with mild, moderate, and severe forms of Central Centrifugal Cicatricial Alopecia (CCCA) or controls. We chose to study these four proteins based on studies in a mouse model of CCCA. All four proteins were reduced in the basal layer of the epidermis as the disease progressed. The protein involved in RA action (retinoic acid receptor beta, RARB) was also reduced in the sweat glands and several different types of cells in the dermis surrounding the hair follicle as disease progressed. However, there were no differences in these proteins in the hair follicles or sebaceous glands.

Conclusion

Since RA directly regulates RARB, this suggests that the amount of RA in the epidermis, dermis, and sweat glands is reduced as the disease becomes more severe. Treatments to improve RA synthesis and action may delay the progression of CCCA. But treating with RA or one of its synthetic derivatives (Isotretinoin/Accutane, tretinoin/Retin A, acitretin/Soriatane) may not be effective, as RA cannot function effectively without its receptor. There are three receptors for RA and future studies should examine the other two receptors to determine if they are also reduced as this disease becomes more severe.

Acknowledgment

Wilma Bergfeld and Natasha Mesinkovska at the Cleveland Clinic were essential in obtaining samples for this study.

RESEARCH FINDINGS

2013 CARF Research Grant Recipients: Matthew J. Harries, PhD, FRCP, and Ralf Paus, MD

Research Study:

“Epithelial-Mesenchymal Transition in Lichen Planopilaris (LPP)”

Biography

Dr. Matthew Harries received his medical degree in 1998 from the University of Leeds, UK. In 2001, he gained membership in the Royal College of Physicians of London, and in January 2003 took a post as a Resident in Dermatology in Manchester. During training, he took time out of programme to study the hair immune system in primary cicatricial alopecias, working as a Clinical Research Fellow at the University of Manchester, and a visiting Research Fellow in Experimental Dermatology at the University of Lübeck, Germany. He was awarded a PhD from the University of Manchester in 2011. He now works as a Consultant Dermatologist at Salford Royal NHS Foundation Trust in Manchester and is an Honorary Senior Lecturer at the University of Manchester.

Professor Paus studied medicine at the Universities of Würzburg, Berlin, and Vienna. He studied for his MD thesis at the University of South Florida, Tampa, USA, and undertook internships at the University Hospitals of Basle and Zurich, Switzerland. He graduated from the Free University of Berlin in 1987. Following post-doctoral research at Yale University (1987-90), he trained as a clinical dermatologist in Berlin, where he became Consultant Dermatologist and Junior Faculty at the Charité University Hospital. From 1999–2004, he served as Professor and Vice-Chair of the Dept. of Dermatology, University Hospital Hamburg-Eppendorf, University of Hamburg. He was Visiting Scholar at the University of California, San Diego (1992), Visiting Professor at the Dept. of Molecular Medicine at the Max-Planck-Institute for Biochemistry, Munich-Martinsried (2005), and Honorary Visiting Professor at the University of Bradford until 2010 and again since 2012. He was Head of Experimental Dermatology, University of Lübeck, Germany from 2005–2013. Professor Paus is currently the Professor of Cutaneous Medicine, University of Manchester, UK, and heads the Laboratory for Hair Research and Regenerative Medicine at the Dept. of Dermatology, University of Münster, Germany. He has been Editor of *Experimental Dermatology* since 2007.



Matthew J. Harries, PhD, FRCP



Ralf Paus, MD

Background

Previous studies of Cicatricial (scarring) Alopecia, including from our own lab, have focused on inflammation-induced damage to hair follicle stem cells as the cause of hair loss. However, this does not fully explain why hair follicles are replaced by fibrous scars. Preliminary work from another study from our laboratory (also partly funded by CARF) suggested that hair follicle stem cells (i.e., cells that make a hair follicle and/or a shaft) may change into mesenchymal cells (i.e. cells that make scar tissue). This process is termed Epithelial-Mesenchymal Transition (EMT) and can be seen in other fibrotic diseases, some cancers, and in wound healing. Here, we have explored the hypothesis that hair follicle stem cells not only die due to excessive inflammation, but that at least some of them also undergo EMT and thus are irreversibly replaced by scar tissue.

Research

Using affected and unaffected samples from people with LPP, we looked at a number of markers that are typically seen either in epithelial or mesenchymal cells, or are involved in regulating these markers. We found increased expression of mesenchymal markers and reduced expression of epithelial markers within affected hair follicles, suggesting that EMT is occurring in these cells. We also attempted to see if we could make normal hair follicles show evidence of EMT by growing these hair follicles in the laboratory and treating them with known triggers of EMT. This again showed increased mesenchymal markers and reduced epithelial markers within the hair follicle stem cell region. This model suggests that if hair follicle stem cells are placed in the right environment, they can be induced to undergo EMT. Further, this model can now be used to study potential treatments to prevent or reverse EMT, especially since we have been able to identify key molecular signals that induce or prevent EMT.

Conclusion

These data suggest that hair follicle stem cells in LPP are changing their behavior from cells that can make hair to cells that cause scarring (fibrosis). This process can also be imitated and induced in the laboratory, and can be prevented by a drug that is already available to patients. This current work provides a key basis for dissecting the molecular drivers of this “stem cell-to-scar” transformation, and for identifying novel strategies how to reverse this scarring process. Our novel findings suggest that future treatment of LPP will need to target both the inflammation seen in this condition whilst also preventing EMT. This work is currently under review with the #1 journal in pathology research, that is, the *Journal of Pathology*.

Acknowledgment

We thank Drs. Hisayoshi Imanishi, David Ansell, Norbert Sepp, and Christopher Ward who co-authored this paper and provided crucial input, as well as CARF for providing partial funding for this translational LPP research project.

RESEARCH FINDINGS

2013 CARF Research Grant Recipients: Christopher Potter, PhD & C. Herbert Pratt, PhD

Research Study: “Cicatricial Alopecia in Tal1 Mutant Mice”

Background

Cicatricial Alopecia (CA) is a disfiguring skin disease that results in destruction of the hair follicles and scar formation. Numerous mouse models provide tools to investigate the underlying molecular and biochemical pathways that predictably and reproducibly lead to follicular scarring as seen in human CA.

Research

C3Fe;B6-Tal1Hpt (Hairpatches) is a new mouse model of CA whose skin phenotype has not been well characterized. This study aimed to investigate the development and progression of CA in the Tal1Hpt mouse by evaluating the histopathological and transcriptome changes in the skin of these mice over time, using well-established histopathological techniques, as well as high-throughput mRNA sequencing modalities. Understanding the pathogenesis and gene networks underlying the CA in these mutants will provide needed basic information on the pathogenesis of CA.

Histopathological screening of Hairpatches mice revealed thickening of the upper layer of the skin (epidermis), as well as marked scarring of remnant hair follicles. Preliminary skin lipid analysis showed changes in both wax monoesters and diesters between mutant and normal mice. Lastly, RNA sequencing revealed changes in the expression pattern of several genes.

Conclusion

Cicatricial Alopecia is a disfiguring skin disease that results in follicular destruction and scar formation. Numerous mouse models provide tools to investigate the underlying molecular and biochemical abnormalities that predictably and reproducibly lead to follicular scarring as seen in human CA. Hairpatches is a new mouse model of CA whose skin, lipid, and gene expression changes during the disease process indicate that this mouse would be a good model of CA in humans. Understanding the pathogenesis and gene networks underlying the CA in these mutants provides needed basic information on the pathogenesis of CA. We are in the process of preparing a manuscript, as well as additional NIH grant applications to further the work on this mouse model.

Two Research Grants Awarded by CARF in 2015

By John P. Sundberg, DVM, PhD, Chair, CARF Scientific Advisors

We know that while Cicatricial Alopecias are a group of diseases, they all involve hair follicle inflammation and ultimately result in hair follicle scarring, which is manifest clinically as permanent hair loss. However, we do not yet know why some people and some hair follicles are affected while others are not. To that end, CARF has an ongoing program to fund researchers who study these problems. 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 Dr. Yolanda M. Lenzy, Medical Director, Lenzy Dermatology & Hair Loss Center & Clinical Associate, University of Connecticut Health Sciences Center Department of Dermatology, Farmington, CT. The purpose of this study is to determine the prevalence of Central Centrifugal Cicatricial Alopecia (CCCA) among a cohort of African American women across the United States and to examine the independent and interactive role of hair grooming practices, genetics, other forms of concomitant hair loss, inflammatory conditions, and nonmalignant growths. This study will utilize the Black Women’s Health Study (BWHS), which began in 1995 when 59,000 women (median age, 38) from across the United States enrolled. The BWHS has successfully followed participants with biennial questionnaires for data on incident disease and medical, reproductive, behavioral, psychosocial, and socioeconomic factors. The study has linked addresses to U.S. census data and to air pollution data.

The second project is led by Dr. Herbert Pratt, Department of Genetic Resources Sciences, The Jackson Laboratory, Bar Harbor, Maine. His project matches a pilot project funded by the West Coast Metabolomics Center at the University of California, Davis, California. CARF is helping to support collection of skin surface lipids from a variety of mouse models that develop various forms of Cicatricial Alopecia and controls. Working with Dr. Lloyd E. King, Jr., Director of the Vanderbilt Hair Clinic, Vanderbilt University, Nashville, Tennessee, similar samples will be collected from human patients with Cicatricial Alopecia and unaffected individuals. This will begin to investigate the hypothesis that abnormalities in lipid production by the sebaceous glands is the underlying initiating factor in some forms of Cicatricial Alopecia. Using state-of-the-art lipidomics technology, these investigators will investigate whether or not specific changes in skin surface lipid profiles are associated with different forms of Cicatricial Alopecia. As the underlying genetic cause is known in the mice, this may point to the underlying causes in human patients, which can be investigated with next generation sequencing in the future.

We are organizing a satellite symposium in May associated with the annual meeting of the Society for Investigative Dermatology where they will be encouraged to present their findings. Although we do not expect a major result in one year, we hope for promising leads and that their data will be a critical component of future grant applications to the National Institutes of Health and other organizations. These grants are critical to encourage gifted researchers to continue their work on this very difficult medical condition.

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(<http://www.rarediseases.org/>)



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

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

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