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Issue XXII

CARF Communiqué

Boost Your Brows (and Your Confidence!)

By Adriana Schmidt, MD

Eyebrows are important to our cosmetic appearance, particularly because they frame our eyes. The shape and density of eyebrows is also an important component of our attractiveness. Eyebrow thinning and loss can be a devastating part of the alopecia experience. There is, however, a range of options for re-creating the eyebrows, from makeup to cosmetic tattoo.

In early or minimal eyebrow loss or thinning, you may wish to experiment with brow makeup, at-home tattoos, or prostheses (fake brows you can stick on). Learning how to use makeup and stick-on products is not easy for most of us and takes some patience! One online site we have found particularly resourceful for all products related to brows is <https://www.headcovers.com/eyebrows/>. In addition, stores like Sephora employ specialists who can assist you in choosing the correct color to match your skin tone and enhance your eyebrows. Eyebrow extensions are another option but these require that you have existing eyebrow hair.

When makeup or temporary fixes become too time-consuming or don't provide enough coverage, consider cosmetic tattoos. There are a lot of cosmetic tattoo specialists across the country. One way to choose one would be to ask your friends who tattooed their brows (if you like the results, of course!). Another is to ask your dermatologist for recommendations. Finally, there is a website that provides information on cosmetic tattooing and the specialists who have gone through specialized training for tattooing on the face. This and other useful information can be found at the Society of Permanent Cosmetic Professionals website, or www.spcp.org.

In recent years, microblading (also known as microstroking, micropigmentation, eyebrow feathering and 3D eyebrows) has become increasingly popular. Like cosmetic tattooing, microblading is performed by a specialist at salons. Unlike cosmetic tattooing, microblading is considered semi-permanent and may not last as long before fading and needing to be redone. This is because pigment is deposited higher up in the skin. Also, the type of pigment used for microblading has an iron oxide base, which allows the color to softly fade over time unlike the inks used in permanent cosmetic tattoos. The microblading technique uses a specialized, hand-controlled tool to make fine cuts in the skin to implant pigment that resembles the appearance of natural eyebrow hair.



Before (left) and after (right) microblading procedure in Los Angeles, California.

Some complications of cosmetic tattoos are similar to complications of tattoos in general. These include allergic reaction to the tattoo dye; use of incorrect pigment so that the tattoo looks unnatural; undesirable shape or pigment deposition; fading of pigment over time; granuloma formation, which is a scar-like mass that forms around the foreign substance deposited in the skin; and scarring. In addition, unsterile tattoo equipment can transmit infections such as hepatitis C. Of note, caution should be exercised when individuals with cosmetic tattoos get an MRI due to reports of tingling and burning at the site.¹

Cosmetic techniques continue to improve that will allow us to re-create a more natural-appearing brow. We hope you continue to become informed through our CARF community, these newsletters, and CARF support groups in your area. Stay tuned!

Reference

1. Tope, W.D., and F.G. Shellock. Magnetic resonance imaging and permanent cosmetics (tattoos): survey of complications and adverse events. *J Magn Reson Imaging*. 2002; 15:180-184.

www.CARFintl.org

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Question
of the Month.

<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

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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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PATIENT CORNER

Folliculitis Decalvans from a Male Perspective

By Dr. Patrick Maile

I was diagnosed with folliculitis decalvans several years ago and have tried several different treatments. Not only am I a patient, but I am also a physician in training, which has helped provide a lot of insight into the condition.

Although I am by no means cured, I am currently on a regimen that has for the most part kept my symptoms under control, which includes:

- Doxycycline 100 mg PO daily
- Ketoconazole 2% shampoo applied daily
- Neutrogena acne cleanser applied daily
- Fish oil/Vitamin D (1000 IU) combo capsule taken daily
- Turmeric supplements taken daily

At one point, I was also using topical steroids, but I stopped them so that I would not ruin the scalp micropigmentation (SMP) treatments I received, mentioned below. Also, avoidance of sunlight as much as possible is imperative, especially since I shave my head.

As far as camouflage, this may not be applicable to the female patients, but I underwent SMP to conceal some of the scarring that was present. It not only helped conceal the scarring caused by the folliculitis decalvans, but it also helped conceal the linear transplant scar I have from a hair transplant surgery.

Hope this helps!

The Emotional Side of Cicatricial Alopecia

By Rosemary Perugini

Hello my name is Rose and I was diagnosed with CCCA a year ago. I will call it scarring alopecia because it is much easier to pronounce. I had been using various hair loss remedies for the past 10 years that I finally gave up and went to see a dermatologist once again. I had a biopsy done and it was confirmed that I had scarring alopecia and there was nothing they could do but try to stop the inflammation. They tried to stop it by giving me six painful injections into my scalp that brought tears to my eyes. They told me it was caused by a series of events in my lifetime. The first was using chemical products and braiding my hair too tightly, which caused my hair follicles to react to the stress and stopped the hair growth cycle. The second was being severely anemic caused by having gastric bypass surgery in 2008. This caused a bad reaction or side effect that left me unable to absorb nutrients properly and now I am nutritionally deficient, which may have affected my hair. That also has had a terrible effect on my vitamins and minerals necessary to grow long healthy hair.

I also had a low thyroid condition that is known to cause hair loss and other health issues. So I've been living in Florida for 8 years and dread the summers because I have to wear a wig every day. Living in a city or state that is extremely hot and irritable 9 months out of the year with a wig on is just unbearable. I'm desperate and research weekly on new research on discoveries for hair loss cures or restoration technology. I pray one day that we sufferers will find a cure or new restoration technique that will help us to live a happier and more peaceful life.

There have been some breakthroughs, but the cost has been out of reach for thousands of us. The shame and cover-up we have to endure each day is tremendous. Hoping that the wind won't blow our hairpiece off and to have to hide in shame. Life is painful at times, and now I have to add another routine in order to be pain-free and less depressed. The best treatments would be to stop the inflammation that causes the cells to not grow hair and stop the energy flow to the scalp.

I've been reading many books on hair loss causes and regrowth from doctors and scientists all around the world that have been studying the causes of hair loss in women and men and children. So far, the main culprit is the inflammation in the body that must be reduced or removed in order to see any improvement.

I believe it is a good practice to keep up with the latest scientific news so that we can all contribute to each others healing by helping fund the research or set up a fund for the alopecia group to get the devices or medications resources we need to be able to feel better about ourselves and love ourselves more. I will continue to read and write to share these findings.

PATIENT CORNER

Find a haircut that suits you!

By Barbara Borkgren

I was diagnosed in 2004 by Dr. Vera Price with Cicatricial Alopecia. It was personally a shocking diagnosis. No one, even the men, in my family for generations had hair loss. I admit that I am a vain woman. My hair was my glory. It had always been thick and glossy and I loved the attention and compliments it had always gleaned. I held my head up and tried to come to grips with what was going on. I needed to separate my ego from my hair, literally.

After several years of trying all sorts of hairpieces and wigs, I realized I was actually lucky. I had found a wig style that brought compliments and suited my personality. Now I never have a bad hair day. Further, I never have a bad haircut! I simply smile and say thank you when someone comments on how cute my cut is.

My advice is: find someone with talent to help you find the right style and then have your wig or hairpiece trimmed and thinned to suit you.

Giving and Getting

By Marilyn Ey

Patient Outreach Volunteers (POV) help those affected by cicatricial alopecia.

POV Nancy wanted to introduce me to “J,” a CICAL (cicatricial alopecia patient) who lives in the UK. I immediately sent an email to J. For two weeks, no response. Then POV Nancy learned J never received my email. So I sent it again.

A few days later, my dermatologist said, “Rapid hair loss.” I wanted to cry, scream, and throw things. Then depression set in. Slow, deep breathing exercises helped, but what I really needed was someone who understood my emotional meltdown. My CICAL support friends were unavailable. Drat.

Years ago, I experienced CICAL depression. Here I was miserable again. Then I heard “ding” as J’s email arrived. Her CICAL story pulled my heart strings. I immediately replied, shared some tips and tricks, and encouraged her to reduce stress, to quit worrying about CICAL 24/7, and to start enjoying life again. As my email headed across the pond, I realized my stress, anger, and depression were gone. YES! J’s email arrived at the perfect time...a time when this POV was in need.

By GIVING to J...I was GETTING so much more in return.

Need support? Feeling alone? Request POV contact at info@carfintl.org.

Looking Ahead to Summer

Swim with confidence in a soft nammu swim cap. Order from nammuhats.com (discount code NDGC15 at check out) or on Amazon.com.

This summer keep CICAL cool with a ventilating hat and cooling cloth.



nammu swim cap



ventilating hat and cooling cloth

PATIENT CORNER

Greetings from Scotland!

By Aileen Pepin

My name is Aileen Pepin, a 65-year-old female and a retired school teacher who lives in the town of Falkirk, Scotland, UK, with my husband, Nick. I have two adult sons and three grandchildren.

And a beautiful chocolate cocker spaniel!

I have been diagnosed with Frontal Fibrosing Alopecia. I know that this is an autoimmune disease. I had a biopsy done about a year ago at Forth Valley Hospital that confirmed this.

I first noticed a few small areas of bald patches at the front of my hair while my husband and I were holidaying in India in January 2015,

and I was concerned enough to visit my doctor on returning home. After a couple more visits to my general practitioner, I was referred to a dermatologist at my local hospital and it was there that I was introduced to the term “scarring” alopecia and sent for a biopsy.

My hair loss has been quite slow—and, of course, permanent—and I have several bald spots, all at the front near my fringe. The quality of my hair is also poor (I never had thick hair), and until recently, I had been able to style my hair so that the bald areas were hidden, but this is becoming more difficult.

I also have hair loss at the sides of my hair near my ears.

I have tried taking natural food supplements and I eat a vegetarian diet. I have been using scalp serums and special shampoos but to no avail. My dermatologist gave me a steroid gel (Synalar) to apply to reduce inflammation, and I use this when I notice any redness. I did take part in a research programme with a London Hospital but no feedback is available.

I am not keen to wear a wig, but recently have started to do so, and with the encouragement of my supportive husband and close family members, I’m beginning to come to terms with this. I do get upset when I’m drying my hair after showering each day and see the bald patches and, as it’s a daily activity and repetitive, I’ve begun to dread these times.

I do always try to remind myself that alopecia is not a life-threatening condition, but living with it can be psychologically difficult. I am not, however, ready to join a support group.

I have not worn my wig to places where I know a lot of people, but this will happen very soon, I believe.

My dermatologist has not asked to see me again, so I feel a little abandoned in that area.

It’s a waiting game. What awaits me—complete or partial baldness? I hope that someday a cure will be found.



Present day (left) and one year ago (right)



My new wig

SUPPORT GROUP NEWS

Report from Boston

The Boston Support Group has met regularly (every 3-4 months) since November 2, 2009. We are a lively (though introspective) group of rotating regulars and newbies who talk, listen, emote, and support each other in a beautiful conference room provided by dermatologist Dr. Debra Scott at The Brigham and Women's Ambulatory Care Center (850 Boylston St., Chestnut Hill, MA) in Fishbowl A Conference Room from 2:30-4:30PM.

Patricia Wrixon, owner of The Salon at 10 Newbury, will be joining us for the June 4th meeting (2:30-4:30PM). Ms. Wrixon is an expert in the art of women's hair replacement, and in addition, she has a non-profit, Wigs for Well-Being, which provides wigs for women undergoing medical treatment. We recommend that group members bring their questions about wigs and other solutions for hair loss to this session.

We are fortunate that Dr. Lynne Goldberg, Professor of Dermatology and Pathology, BU School of Medicine, Director, Hair Clinic, Boston Medical Center, attends all of our meetings to answer questions and monitor the discussion for accuracy.

Please join us!! If you can, RSVP to Lori at lori.ali1023@gmail.com. Hope to see you there!

For more information about CARF and the Cicatricial Alopecias, go to: <http://www.carfintl.org>.

Report from Los Angeles

By Adriana Schmidt, MD

We meet three times yearly at my office in Santa Monica, California, on a Sunday morning. Typically, there are about eight women who join and we discuss the following:

- Finding the right place to buy a wig is very important and often we rely on word-of-mouth. We discussed wig vendors in the LA and Orange County Area. Interestingly, half the women had been to either one place or the other and were divided on whether they enjoyed the products, experience, or value. So, perhaps it is not easy to universally recommend a place; you might just need to check for yourself!
- Although we aren't sure whether mineral sunscreens cause scarring alopecia, it's probably safest to avoid them. These are sunscreens that contain zinc oxide and titanium dioxide.
- One of our patients had a wonderful experience with microblading to re-create eyebrows she had lost with FFA. She is very happy with the outcome and everyone else was impressed by how good they look.
- One woman spoke about her positive experience attending the CARF patient conferences in Chicago and New Orleans and recommended that the group consider going. She has formed nice friendships among the attendees and there was continuity after attending the first conference. She learned a lot of valuable information, and she values the fact that the specialists attend from all over the country.
- We discussed meditation. Two attendees have been going to free community meditation groups in their area and find that it has begun to teach them to be present in the moment, which is refreshing!

Looking to connect with others who have Cicatricial Alopecia? Join the "Let's Put Out the Fire" Facebook group.

Visit <https://www.facebook.com/groups/179660093699/> and request to join. This is a closed group, open only to medical doctors and patients with Cicatricial Alopecia (LPP, FFA, CCCA, etc.). To maintain the integrity of the group, the group administrators request you send a brief description of your condition to lppletsputoutthefire@gmail.com along with your request to join. This group does not offer any medical advice, all comments and postings are the sole responsibility of their writers. Please consult your physician before making any healthcare decisions.

SUPPORT GROUP NEWS

Report from San Francisco

By Marilyn Ey (Support Group Leader)

Topics Discussed at Our Meetings

- Hairpieces are attached using clips, double-sided tape, or both. For tape instructions, see page 21 of the November 2016 CARF Communiqué Newsletter.
- As “wisdom highlights” (aka gray hair) increase, hairpiece coloring should change to match.
- A good hair style cut makes all the difference.
- Consider allergy tests to find out what is bad for you.
- “The Wahl Project,” by Dr. Terry Wahl, discusses diet and supplements.
- Consider visiting a functional medical doctor who addresses the underlying cause of a disease.
- Turmeric with black pepper is a supplement used to help reduce inflammation. Studies in India recommend the combination of Turmeric, black pepper, and a small amount of fat for better absorption.
- Certain laundry detergents increase clothing SPF.
- The metal particles in eyebrow tattoos means you can’t have an MRI. Softap Inc. (www.softap.com) offers permanent ink eyebrows. Ingredients include only a small amount of iron oxide. The Softap location in Livermore, CA, reported about 2% of clients experience some feelings in the eyebrows during an MRI. For more MRI details, go to www.mrisafety.com.
- Milder cases of cicatricial alopecia (CICAL) can burn out. Burn out is a term used to describe inactive CICAL. Central centrifugal cicatricial alopecia (CCCA) is easier to get under control than FD, FFA, LPP, etc.
- Cold helps reduce inflammation. Apply a frozen bag of peas or cold compress to CICAL-affected areas.
- Sweat exacerbates hair follicle inflammation. Remove sweat by immediately shampooing or using a cleansing wipe. To remove sweat during workouts, use tissues dunked in cheap vodka. Tissues and vodka are easily stored in Ziploc bags. Salicylic acid is another cleanser. To reduce sweating, wear a cooling cloth. Consider “non-sweating” forms of exercise.
- Interested in purchasing a cooling cloth? Check out retail locations: Lowe’s, Home Depot, Dick’s Sporting Goods, Bed, Bath & Beyond, and Brookstone. Lowe’s also sells cooling hats. Google “cooling cloth.” We prefer cooling cloths made of fabric rather than rubber based.
- One lady said, “I’m from Kentucky, so I have good hats!” Hats prevent the sun’s heat from inflaming hair follicles. During hot weather, a well-ventilated hat allows heat to escape. Direct sunlight causes pain for some CICALs. Sometimes, it feels like your scalp is on fire. If you are affected, stay in the shade, wear hats, or use an umbrella/parasol to avoid sun exposure.
- A nammu swim cap is soft, comfortable, and stylish. Wearing it poolside continues to cool the scalp. (See page 4 for photo of nammu swim cap.) Find colors and styles at nammuhats.com or Amazon.com.
- Perifollicular is pronounced “Perry foe lick you lar.” Using words like hydroxycloquine (hi drox ee clor oh quinn), cicatricial (sick ah trish ul), and lymphocytic (lim foe sit ick) makes us sound like doctors. For more pronunciations see *CARF Communiqué*, May 2012, page 9, and May 2016, page 6, “Tongue Twisters.”
- Ketoconazole shampoo is used for dandruff, but also helps with inflammation.
- Derma Smooth (Fluocinolone Acetonide) Topical Oil is a mild topical steroid prescription. Patient tip: Wearing a shower cap to protect your pillow is awkward and noisy. Instead of wearing the cap, put three old pillow cases around your pillow.
- There are two cicatricial alopecia categories: lymphocytic and neutrophilic. The neutrophilic form is bacteria based. Folliculitis decalvans (FD) is neutrophilic. A CICAL with FD chose to have laser hair reduction using YAG. By destroying his hair follicles, he not only loses hair, but the itching, pain, and fluid secretions. He hopes to eventually eliminate taking antibiotics.
- Low level light therapy (LLLT), aka “cold laser therapy,” can reduce inflammation. One woman treated half her scalp using LLLT 635 nanometers three times a week. Seven weeks later, the treated side had significant inflammation reduction. Her dermatologist took photos to document the difference. Consider LLLT sessions to see if it helps. LLLT wands and caps (www.Capillus.com) were discussed at the New Orleans Conference.
- Members asked why I’m a CARF Volunteer? The answer is simple. When I was a first diagnosed, a CARF volunteer helped me. See “The Power of One,” *CARF Communiqué*, Spring 2011, page 8. To read all newsletters, go to carfintl.org. On the main page, click on “For Patients.” Next, click on “Newsletter” and follow instructions at the bottom of the page. Tip: Save your “member number” in your computer or smartphone Contacts.
- What is the best beauty secret? A smile!

MEETINGS, ADVOCACY & AWARENESS

Message from the Chairman of the Board

By Rita Wanser

Happy spring to all! I hope your year has brought good things. It has been a great year for me both personally and professionally and I wish you all the same fortune. I am always happy when asked to share a few words about CARF for the Communiqué. CARF is a significant part of my “free” time, which then leads me to wonder how we actually get to do the things we do for you!

Awareness activities continue to increase engagement with new patients, family members, and physicians. Not only do we use the Communiqué to speak to CARF activities, but we have increased our presence on Facebook; and yes, we do have a Facebook page! We invite you to look at the page and follow CARF as a way to hear news more routinely. We are building our LinkedIn presence and that should be visible in the next few weeks. These both are part of our efforts to increase awareness and keep everyone informed on happenings within the hair community. We also look to this as an opportunity to reach interested researchers, physicians, industry representatives, and potential donors.

At the North American Hair Research Society meetings, it was shared that the newest research on the hair follicle may lead to a directional understanding of the cicatricial alopecias. Our Executive Director, Victoria Ceh, provides highlights from our open meeting at the American Academy of Dermatology on page 9 of this issue. Attendance at this meeting increases each year, as more physicians want to hear about the cicatricial alopecias and are active in their pursuit of research. The meeting is always a great opportunity for interested physicians to speak directly with our scientific advisors and physician board members. I would be remiss if I did not mention our working committees that have developed or implemented awareness plans, website updates, and updates to survey development for CCCA and FFA.

A huge THANK YOU to the volunteers who are always willing to help when asked, or who come to us independently about small fundraisers or awareness building activities. I now put out the challenge to all of the rest of our CARF subscribers to get actively engaged with CARF. It is not just rhetoric when I write about the amount of work that a very small group of volunteers do for you. I am in awe of the scientific researchers and clinicians that freely give of their time to this organization, and to you.

I cringe every time we get a message complaining that all we do is ask for money but offer no treatments, causes, or cures. We are not frivolous spenders; we spend many hours trying to maximize our efforts with minimal people and financial support. Surprisingly, we have been successful in fulfilling goals from each of our pillars of our mission.

Waiting for scientific breakthroughs can be frustrating; we all wish things could move faster. For those of you who are aware of the breakthroughs on alopecia areata, I remind you that this has happened over a 20-year period of time. It has also happened because patients, their family members, and others have been actively engaged and have made significant financial contributions throughout that time.

I have been involved in research activities for most of my professional career. Research is a long process and I can only say that for the very small time there has been an organized effort for those with a cicatricial alopecia, there have been many strides. It may not seem like it when you are anxious to better understand your condition and have a treatment or cure. Just know that we are very lucky to have **THE BEST OF THE BEST** researchers and clinicians involved in CARF, and we are energized by the interest in cicatricial alopecia from the next generation of LEADING physicians and researchers.

If finances were such that we could provide large grants, we certainly would. Rather than being deterred by the financial challenges of supporting research studies, our scientific advisors continue to request proposals that we can contribute to should the advisors find merit in the proposed scientific approach. We have modified our mission to promote research, and we are very active in keeping up on the basic research and clinical studies, and in bringing the researchers together to find a common path and direction for understanding the cicatricial alopecias. Kudos to our lead scientific advisor, John Sundberg, for his efforts at last year’s Society of Investigative Dermatology (SID) meeting in creating a strong program with a direct approach to understanding cicatricial alopecia. The researchers just met again in a less formal way at this year’s SID meeting. I look forward to sharing the results of that meeting via Facebook or e-mail.

To those who are involved in CARF, please continue these wonderful efforts. To those who are not currently engaged in our organization, I ask that you become involved. We will be putting out a call for very specific needs in the near future, but do not wait if you have ideas on how you’d like to get involved. We want to hear about your awareness and fundraising ideas now. Send an email to info@carfintl.org and someone will respond to you.

My best regards to you all. Rita



Rita Wanser

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 CARE.

Please consider making a donation to CARF so we can continue to advance our mission. 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: <http://www.carfintl.org/donations.php>.

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

MEETINGS, ADVOCACY & AWARENESS

Updates from CARF Website and Technology Work Group

If you haven't been to the CARF website lately, go now and check out some of the changes that the CARF Website and Technology Work Group has been working on. In addition to providing accurate and up-to-date material on diagnoses, the goal is to make the site a dynamic source of ongoing information. New features include the addition of a "Question of the Month" posted by Dr. Lynne Goldberg and video highlights from the 2016 Patient-Doctor Conference including links to three lectures given at the conference. If you have any suggestions about content you would like to see on the website or if you would like to volunteer to help with technology efforts, please contact Melanie Stancampiano (mstancampiano@carfintl.org).

The work group consists of Dr. Paradi Mirmirani (chair), Mike Andre (webmaster), Dr. Lynne Goldberg, Dr. Nisha Desai, Dr. Corey Hartman, Dr. Chris Janus, and Melanie Stancampiano (staff). (<http://www.carfintl.org>)

Updates from CARF Cosmetology Industry Work Group

"An ounce of prevention is worth a pound of cure." This old adage is especially true for cicatricial alopecia. The sooner it can be identified, the more likely a patient is to be able to halt or slow its progression. And if it could be prevented, all the better.

Hair stylists are on the front lines of alopecia identification. They see more of our hair and scalp than we probably ever will. The leadership of CARF recognized this untapped resource and assembled the CARF Cosmetology Work Group specifically to reach out to hair stylists and arm them with valuable information about signs and symptoms of cicatricial alopecia. The group, headed by Dr. Kimberly Salkey, has made strides toward incorporating education about scarring alopecia into cosmetology school curricula across the United States. They have developed a reference card for stylists to facilitate rapid identification of different forms of scarring alopecia. It will be distributed in an electronic format to stylists, encouraging them to refer their clients to see a dermatologist as soon as possible, and to reach out to CARF, if they think they detect a cicatricial alopecia.

Other members of the work group are Dr. Amy McMichael, Dr. Valerie Callendar, Dr. Yolanda Lenzy, Dr. Achiamah Osei-Tutu, Christina Arungwa, and Melanie Stancampiano (staff). We are grateful for efforts and energy of this work group.

Cicatricial Alopecia Open Meeting at AAD Annual Meeting Saturday/March 4, 2017, 8:00am–10:00am Hyatt Regency Orlando, Meeting Room: Celebration 4



At the American Academy of Dermatology Meeting in Orlando, F, a group of 20 physicians, CARF Board members, and staff gathered for a lively discussion about cicatricial alopecia. Representatives from each of the work groups provided updates on their projects, including increased awareness in the hair styling community and continued improvements to the CARF website and online process.

Exciting discussion took place among physicians who are currently running cicatricial alopecia research projects. Drs. Elise Olsen, Shalini Krishnasamy, Maryanne Senna, and Apostolos Pappas all provided updates related to their work. As a result of this conversation, CARF has developed the CICAL Research Collaboration Work Group and invited several physicians and board members to participate. CARF will continue to provide updates on these research studies, including how those who are interested may participate.

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

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CLINICAL TRIALS & RESEARCH STUDIES— RECRUITING PATIENTS

Frontal Fibrosing Alopecia Study – UK Participants

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

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

Topical Gabapentin Study

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

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

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

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



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(<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: For more information, contact Susan at losangelessupportgroup@carfintl.org

San Diego: For more information, contact Mary at sandiegosupportgroup@carfintl.org

San Francisco: For more information, contact Marilyn at sanfranciscosupportgroup@carfintl.org

ILLINOIS

Chicago: For more information, contact Joe and Bev at chicagosupportgroup@carfintl.org

LOUISIANA

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

MARYLAND, WASHINGTON DC, VIRGINIA

For more information, contact Beth at md-dc-va-supportgroup@carfintl.org

MASSACHUSETTS

Boston: For more information, contact Melody, Doreen, and Joyce at bostonsupportgroup@carfintl.org

MICHIGAN

Detroit: Contact Virdell at detroitssupportgroup@carfintl.org

MINNESOTA

Minneapolis/St. Paul, for more information contact Corinna at minneapolisupportgroup@carfintl.org

NEW YORK

New York City Area: For more information, contact newyorksupportgroup@carfintl.org

NORTH CAROLINA

Winton/Salem: For more information, contact Travis at winston-salem-sg@carfintl.org

PENNSYLVANIA

Pittsburgh: For more information, contact Lori at pittsburghsupportgroup@carfintl.org

VIRGINIA

Hampton Roads Area: for more information contact Lucretia at HamptonRoadsSupportGroup@carfintl.org

International Support Groups

CANADA

Toronto, Ontario: For more information, contact Shirley at torontosupportgroup@carfintl.org

UK

London: For more information, contact Marva at londonsupportgroup@carfintl.org

Check online for up-to-date schedule of Support Group meeting dates and locations!
<http://www.carfintl.org/support-groups.php>

New Support Group
Launching in San Diego!
Stay tuned for meeting details.