

HEADLINES

The Official Newsletter of the Cicatricial Alopecia Research Foundation

Summer 2020 Vol.32



PRP: A potential treatment for scarring alopecia: what we currently know

By Kayla H Felix, MS Wake Forest School of Medicine; Edited by Maria Hordinsky, MD

Platelet-rich plasma, more commonly known as PRP, is a component of the blood that is rising in popularity for its potential benefits in the treatment of multiple conditions—current research supports the use of PRP for osteoarthritis, wound healing, improvement of acne scars, skin rejuvenation and more (1,2,3). As its popularity continues to grow, more research is being done to determine whether there is a role for PRP in the treatment of several forms of hair loss. At this time, the use of PRP in patients with non-scarring hair loss, such as male and female pattern hair loss, has been promising; treatment has resulted in increases in hair thickness and number of hairs (4).

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CORRESPONDENCE CORNER

Thank you for your work for all of us who live with scarring alopecia. Finding your organization was critical for me when I was diagnosed with CCCA in the spring of 2017.

- Lisa K.

Thank you for moving towards virtual support group meetings. CARF quickly offered members the opportunity to "get together" during a pandemic. We need these personal connections now more than ever - thanks for all you do!

- Pamela J.

Just wanted to reach out to let you know I loved the webinar series! They had great info and the Q & A was amazing!! That, plus the bi-monthly emails and the quarterly newsletter, we really appreciate all you've done to keep us connected! We rely on you more than you know!

- LaTonya S.

I love having CARF videos available for our FFA ladies. Thank you. We are all under stress at various times and often see increased shedding as a result. We also feel very vulnerable with this uncontrollable disease which tends to cause generalized anxiety as well. Videos with new information presented with a soothing tone is be very beneficial. Thank you for all your support!"

- Eve S.



SUMMARY RESULTS

FROM FALL 2019 4PART SURVEY SERIES

300 RESPONDENTS ON AVERAGE PER SURVEY

Median Age - 62 years
 Oldest - 82 years
 Youngest - 28 years
 Female - 93%
 Male - 7%

AGE OF DIAGNOSIS

54% - 40-60 years
 30% - age of 60+
 15% - ages 20-40 years
 1% - before age 19



RANKING OF VALUE AND IMPORTANCE

- 1 Education - having reliable, medically-vetted info and facilitating awareness of among physicians.
- 2 Research - encouraging and funding research towards better treatments.
- 3 Support - having other patients and volunteers for connection.



86% are either comfortable or sometimes comfortable talking about their hair loss.



57%

Regularly see a dermatologist.



16% have been diagnosed with anxiety or depression.



16%

Hairdresser was the first person to validate hair loss as a real issue.

78% Spend less than one hour per week on medical treatments and/or therapies.



39% have confidence in their doctor/dermatologist when treating their scarring hair loss.

WHAT BOTHERS YOU MORE?

74% - Physical Loss of Hair
 26% - Emotional Toll of Coping with Hair Loss



59%

Are currently treating their condition with a medication and/or prescribed treatment.



44% Wear a hair piece, topper or wig everyday.

36% Rarely wear a hair piece, topper or wig.

RANKING ORDER OF MOST ATTENTION

Hair loss on top of head
 Eyebrow Loss
 Hair loss on side of head
 Thinning hair
 Redness, scaling, itchiness on scalp
 Patches of hair loss



45% would consider hair transplant surgery if they were a good candidate.



60% would definitely attend a small support group meeting if it was near their hometown.



72%

Spend 30 minutes or less per day getting ready styling or camouflaging their hair.



My Alopecia Story

BY MELODI FORD

"I actually felt liberated as if a weight had been lifted off my shoulders." At age 17, I decided to study fashion merchandising and modeling for the Oscar De La Renta showroom in London, England. Upon returning to Atlanta, I continued modeling. I did a bit on the runway and a few commercials. One day this client was flipping through my portfolio and stops about half-way through and says, "You're not quite black enough." In that moment, I had so many emotions. I was shocked, insulted, and angry. With that, I knew that I did not want to belong in fashion modeling or acting. It was the mid-80's, though the industry may not have liked my skin-tone or body-type, they did like my hair. I had beautiful shoulder length hair. Strangers often thought it was a wig. I often modeled in hair shows for popular brands like Paul Mitchell and was even featured in two national black hair magazines. In order to keep my hair looking good, I would get a relaxer so the texture was even and easier to manage as I loved to go running and swimming. My stylist would always tell me that I had a sensitive scalp with a strange cowlick at the

crown of my head. This may have been the onset of my CCCA.

Not only did I have the symptoms, I also had a lot of flakes at the crown of my head. I went to see a renowned dermatologist and was diagnosed with seborrheic dermatitis or dry, flaky scalp. I was told to reduce the number of times I washed my hair down to once per week and use Nizoral shampoo on the crown of my head. As a fitness instructor, I had no idea how I was going to manage this dry, flaky scalp with teaching classes several times per week.

After teaching classes, I would be soaked with perspiration from head to toe, so if I didn't wash my hair, it would have a foul smell. I managed to rinse my hair, use a bit of conditioner and style my hair in a ponytail. Sadly, the Nizoral shampoo didn't help and that "cowlick" in the center of my head surely didn't stop itching. By the mid-90's, I had left modeling. I had cut my hair short and was now getting two different texturizers due to my heritage. Nevertheless, I still had issues with my sensitive scalp. We tried product after product but nothing seemed to help the itching and flakes. Commencing in the new millennium, I grew tired of relaxers, decided to go natural and started wearing braids. In five years, my hair was almost to the middle of my back. I received many compliments on my braided hair styles but my scalp still felt like creatures crawling in my head. In going back to the dermatologist, I was once again diagnosed with seborrheic dermatitis. In 2011, I grew tired of braids, so I decided to loc my hair and wore that style for several



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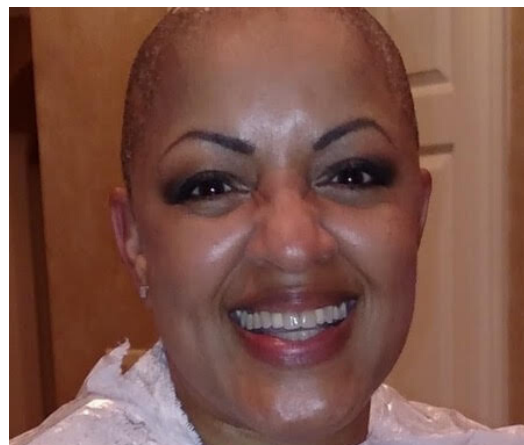
BY MELODI FORD

years. However, they were heavy and hindered my fitness routine. After my stint with locs, I decided to wear my hair in a short natural style and color it blonde. They say blondes have more fun. Still struggling with my scalp, a dear friend suggested I go see her dermatologist. I was hesitant as I had already seen a top dermatologist in Atlanta, but I thought I would give it a try. My scalp was inflamed as I would catch myself digging in my scalp during my sleep. It literally felt as though something was crawling in my head. Additionally, the hair in the center of my head was very thin and one area was completely bald. In 2015, I met with dermatologist Dr. Sherrie-Ann Straughn. With one look at my scalp, she said, "You have a form of alopecia. I wish you came to see me sooner." She suggested we do a biopsy of my scalp in two areas. Upon the lab results, I was diagnosed with central centrifugal cicatricial alopecia or CCCA.

Dr. Straughn explained that the shiny place on my scalp was from scarring and my hair would not grow back in those areas. I had two choices - accept my hair loss or see a specialist for a hair transplant. I decided to accept my hair loss.

A few weeks later, I called my closest sista' friends and invited them to my "Buzz Party" to celebrate me cutting my hair off. We ate and drank wine to celebrate sisterhood. Then my stylist announced, "Are you ready?" I sat in the chair as she turned on her clippers and went right up the back of my head. There was no turning back.

After my head was entirely clean, my friends held up the mirror. I actually felt liberated as if a weight had been lifted off my shoulders. No more trying to hide my bald area with comb twists. The picture was taken right after my hair was cut. You can see the happiness in my eyes. I am now five years into wearing my clean-cut head. I sometimes miss my hair. I wonder if I had been diagnosed earlier, could my outcome have been different? I have to remind myself that this is God's plan. I am just visiting on this planet. I am not fully confident in wearing a clean-cut head. Most people would never know this as I can hide my insecurities very well. I have no desire to wear a wig unless it is for a Halloween party; besides wigs irritate my scalp. I do not know much about my condition but I hope to learn more as I have found my CARF family for support. I pray one day, strangers on the street will stop asking me how long have I had cancer. I think this will help me to better accept my condition and feel more confident in my skin.





MEDICAL & SCIENCE

Continued from page 1

While the data is scarce, we will explore what we know so far about the use of PRP in the treatment of primary scarring alopecia.

What is PRP?

The blood is composed of four main components, one of which is the “plasma” component which contains a combination of proteins that are important for immunity, healing, growth, and anti-inflammatory purposes. While plasma makes up about 55% of the blood’s volume, there is a smaller portion of the plasma that contains a higher-than-normal concentration of platelet cells and special proteins. When isolated, this component of the plasma is called the “platelet-rich” plasma. It contains proteins called growth factors, such as platelet-derived growth factor (PDGF) and TGF-B, which have been found to be important for the regeneration of hair follicles, regulation of hair growth, reduction of inflammation—all of which may contribute to hair restoration (4,5). Other components, such as vascular endothelial growth factor (VEGF), are known to encourage formation of new blood vessels (6). In animal studies, treatment with PRP resulted in increased blood flow and new blood vessels in the treated areas (7).

PRP can be prepared and administered in a variety of ways. In general, a blood sample is placed into a device called a centrifuge and spun at high-speed. Due to the amount of force placed on the sample, components of the blood separate into layers, including a layer of plasma from which PRP is obtained. The centrifuging process can vary in time and speed, and the plasma sample can undergo a variety of steps before it is actually used in treatment, such as additional rounds in the centrifuge or addition of activating factors.

The final product is injected into the scalp. Because it is a fairly new treatment option, there is not currently a standardized “recipe” to prepare PRP for hair loss and no standard number of treatment rounds, so the process may vary by provider.

What does PRP do for scarring hair loss?

At this time, it is unclear whether PRP can be of benefit to those with scarring hair loss. There have been no large studies to assess whether it is an effective treatment, and available information related to PRP as an effective treatment option for those with scarring alopecia is minimal. However, a few patient cases of improvement after the use of PRP have been reported.





MEDICAL & SCIENCE

Continued from page 6

In one patient with central centrifugal cicatricial alopecia (CCCA), there was a greater than 50% improvement in hair density in the top of the scalp after 3 treatment sessions with PRP injections, given 4 weeks apart (8). In a separate patient with lichen planopilaris (LPP), three sessions of treatment with PRP injections to the scalp, hairline and eyebrows also resulted in an overall improvement. There was a decrease in the redness and scaling of the scalp with increased hair density on the scalp and along the hairline, although the eyebrows did not improve after treatment (8). In both patients, there was a loss of hair after the PRP treatments were stopped.

Another case report of a patient with LPP highlights similar improvement after treatment with PRP injections given once per month for 3 months. The patient had a noticeable improvement in scalp itching and hair shedding, along with improvement of scalp redness and scaling (9). In a patient with frontal fibrosing alopecia (FFA), PRP injections given once monthly for 6 months resulted in improvement in itching, scaling, and bumps along the hairline after one month of treatment. It also stopped the progression of hair loss after 5 months (10).

Is PRP a worthwhile option for the treatment of scarring hair loss?

Due to the novelty of PRP as a treatment for

hair loss, we do not yet have the information we need to determine whether it will truly be effective in the treatment of scarring hair loss for most patients. The information mentioned above highlights individual success stories, but more research needs to be done to standardize treatment steps and to study the effect of PRP on a larger number of patients before it can be recommended as an effective treatment.

However, from the small number of case reports that have been released, it appears to be a promising option. Hopefully, more research is on the horizon!

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What is the GEM Club?

The GEM Club is an exclusive group of committed donors who Give Every Month to support CARF's important work. As CARF continues to grow and serve its membership, it's vital that we generate consistent funding to be able to focus on our patient engagements, expand our staffing, preparing more reliable budgets, and planning out our programs. The success of this new monthly giving program will alleviate the stress and financial uncertainty and allow us to continue to offer our exclusive programs and services to the scarring alopecia community.



Membership Levels

Jade GEM Club: \$10 per month

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In breaking down CARF's current annual budget, on average, nearly 80 cents of every dollar raised is allocated toward CARF's current programs and services. The remaining 20 cents is used for the organization's administrative costs to run its operations. Your monthly gifts are precious to CARF and so we've appropriately labeled each monthly giving level by a precious GEMstone that outlines specifically how your gift will be applied. Visit our [website](#) for details.



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Why I became a GEM Club Member and you should too!

Click the video below



Kris Wharton, CARF Board Member



EDUCATION

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This half-day virtual conference is open to all those in the scarring alopecia community and will provide an exclusive opportunity to learn from the country's leading hair loss physicians and researchers --all from the comfort of your very own home!



THE HAIR NECESSITIES

SCARRING HAIR LOSS
VIRTUAL CONFERENCE



THE HAIR NECESSITIES

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Saturday, July 18th, 2020
11AM - 3:30PM EST

Important Dates:

Registration Ends
July 17, 2020 at 5PM

Last Day to Submit Questions
for Live Q & A Sessions:
July 13, 2020 at 5PM



11:00 - Welcome by Rita Wanser

11:05 - The Basics 101 of all Scarring Alopecia Types by Wilma Bergfeld, MD

11:45 - Treatment & Management by Maryanne Senna, MD

12:20 - Novel Disease Pathways in Scarring Alopecia Revealed by Gene Expression Analysis
by Angela Christiano, PhD

1:00 - Surgical Treatments by Nicole Rogers, MD

1:35 - Best Practices in Finding the Right Dermatologist by Jerry Shapiro, MD

2:10 - Platelet -Rich Plasma (PRP) Treatment by Maria Hordinsky, MD

2:35 - Updates on the Use of Lasers Trending for Hair Loss by Ronda Farah, MD

3:00 - The Role of Radical Acceptance in Managing a Chronic Condition by Andrea Furgala, LISW-CP

3:25 - Wrap Up & Announcements by Jean Pickford

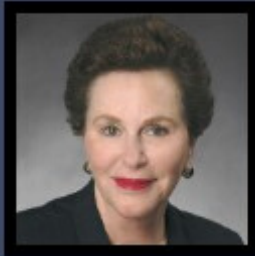
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VIRTUAL SUPPORT GROUPS

“ I am so thankful that CARF launched virtual support groups to make sure we can continue to connect with others in the scarring hair loss community. ”



Virtual SUPPORT GROUPS

CARF is excited to offer its members the opportunity to connect virtually via our Ring Central Platform. This platform allows for video and phone calls to a single platform where members can connect and share from the comfort of their own homes. Currently CARF sponsors 8 support groups across the US. We want to double that number by the fall! If you are interested in leading a support group, please contact [CARF](#) and we will schedule a quick call to get things started!

NEW MICHIGAN VIRTUAL SUPPORT GROUP

Date: Tuesday, July 14th
Time: 7PM - 8:30PM
Click [HERE](#) to RSVP today!



FROM THE DIRECTOR

Dear Members and Friends of CARF,

As I write this report, I am coming up on my third anniversary of being CARF's executive director. A lot has happened over the past three years and I am proud of how much CARF has improved during this time. But I must confess.... I am nowhere near being satisfied and want to be even more proud over the next three years.

There has been a significant shift in everyone's normal practices as we are all affected by the COVID-19 pandemic, and CARF is no exception. We are planning to pivot (did you think of Ross on Friends?) and make some necessary changes in our upcoming planning to help improve CARF's value and sustain ourselves well into the future. Please continue to read as I introduce some new concepts that may likely be coming down the pike. One caveat to mention— as I use the pronoun 'we,' it collectively references our board, staff, and key opinion leaders. It is important for you to know that I gather and meet with these amazing volunteers on a regular basis to provide guidance and input for shaping CARF.

As I have shared with you in the past, the organization has seen exceptional growth in the number of patients who are finding CARF and joining the organization. We believe there are many additional patients, who have no idea CARF exists or who have not actually taken the step of sharing their name to be added to our database. Part of

this outreach is the struggle we have with the name and the name recognition. We know that the word cicatricial, albeit the correct medical term for scarring, is exceedingly difficult to pronounce and spell. Interchanging the word scarring with cicatricial is quite common and readily recognizable to the public. We are planning to start incorporating "scarring hair loss" into a lot of our communications to help pull in those who may not regularly be using the term cicatricial. It will also help those who cannot easily decipher our URL at carfintl.org versus another organization that uses the same acronym. Our intent is to continue to be the CARF that everyone knows, but also cast a wider net to those who are not as familiar.

Another way CARF will be pivoting in the coming months is to incorporate virtual meetings and online learning for our members. We know that many of our members search and read as much as they can on the internet and are extremely well-educated about their hair condition. Patients interact and get information from social media groups and chatrooms, which can be good resources, but must also be screened because of opinion and bias by the contributor.

“ We pride ourselves for publishing information that is always vetted through our expert medical physicians and board of directors. ”

Time and time again, we hear from our members who say they rely on CARF for facts and truths. We pride ourselves for publishing information that is always vetted through our expert medical physicians and board of directors. Everything that is delivered to our members and patients

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is approved and accredited through multiple layers of editors. When an affected patient engages with CARF, it is crucial and reassuring to know that you are getting the best, most reliable, and accurate information as possible.

The results from last year's patient survey (see page 3) clearly demonstrate that access to knowledgeable scarring hair loss doctors is lacking for many of our members. What if CARF offered small groups to virtually meet with physician experts from our board and MSAB for a live Q & A session? This program is seriously being considered, with possible plans for some time in the fall. We know this service will offer tremendous value and increase the importance of CARF in your life.

As these plans are starting to unfold, the concept of a membership structure is also being considered. The perks and benefits of becoming a paying member is still being worked out, but I can guarantee you that we always have your best interest at heart. We are going to make it worth your while to remain engaged and supportive of CARF today and well into the future. In some ways, this current pandemic and state of our nation has provided the catalyst for positive change. It has been our chance to reset and take an inward look of how we impact those around us. CARF wants to impact you in more positive and caring ways, and we are planning to make that happen.

Enjoy the summer and stay well,



Jean R. Pickford



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IN THE KNOW

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Maryanne Makredes Senna, MD is a board certified dermatologist and Assistant Professor of Dermatology at Harvard Medical School. In addition to adult and pediatric general dermatology, she also co-directs the Hair Loss Clinic at MGH and is Principal Investigator of the Hair Academic Research Unit at MGH, a clinical trials research unit dedicated to hair loss disorders.

Click [HERE](#) to view Dr. Senna's webinar on Scarring Alopecia and COVID - 19.

Click [HERE](#) to view Dr. Senna's Webinar on The Mind and Body Connection.



Dr. Jeff Donovan, Medical Director of Donovan Hair Clinic and certified in Dermatology by the Royal College of Physicians and Surgeons of Canada and by the American Academy of Dermatology.

Click [HERE](#) to view Dr. Donovan's webinar on Scarring Alopecia.



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