

# CARF HEADLINES

The Official Newsletter of the Cicatricial Alopecia Research Foundation

Winter 2021 Vol.33



## Hydroxychloroquine use and COVID-19 concerns among alopecia patients: A cross-sectional survey study

By James Pathoulas, Kelly Flanagan, Dr. Chloe J. Walker, Isabel M. Pupo Wiss, Dina Hagigeorges and Dr. Maryanne Senna

The coronavirus disease 2019 (COVID-19) pandemic has caused loss of life and economic disruption. Preliminary studies identified hydroxychloroquine (HCQ) as a COVID-19 treatment. It is thought that HCQ may have in vitro activity against severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) through decreasing viral glycosylation and inhibiting toll-like receptor signaling.<sup>1</sup> While subsequent trials failed to demonstrate efficacy, this remains an active area of research.<sup>2</sup> HCQ is routinely used in the treatment of cicatricial (scarring) alopecia due to its immunomodulatory effects\*.

In this cross-sectional survey study, we evaluated HCQ use among patients with

*Continued on page 8*

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## UPCOMING EVENTS

### February 2021

- 21 CCCA USA Virtual Support Group
- 27 South Africa Virtual Support Group
- 28 Rare Disease Day
- The Mane Event Webinar (1 of 6)

### March 2021

- 21 CCCA USA Virtual Support Group

### April 2021

- 6 San Francisco Virtual Support Group
- 11 New Orleans Virtual Support Group
- 10 Dallas Virtual Support Group
- 13 Michigan Virtual Support Group
- 13 CCCA UK Virtual Support Group
- 14 Maryland Virtual Support Group
- 18 CCCA USA Virtual Support Group
- 24 Tampa Virtual Support Group
- 25 Boston Virtual Support Group
- 26 Atlanta Virtual Support Group
- 27 NYC Virtual Support Group
- The Mane Event Webinar (2 of 6)



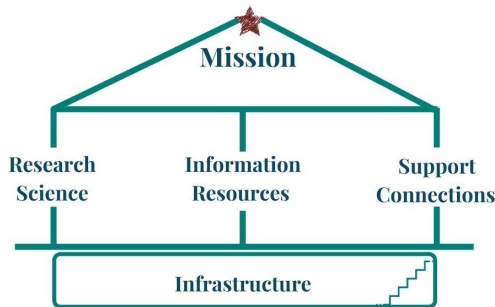


## FROM THE DIRECTOR

### 2021 IS LOOKING BRIGHT

We made it through!! Despite the twists and turns last year, CARF managed to tackle all the challenges that came our way and continued to shine. Although we are not sure what 2021 will bring with regards to the pandemic, we are sure that CARF is entering its most pivotal year yet in our 17-year history.

I have held leadership positions in patient advocacy groups for my whole career and often use pictures and diagrams to breakdown complex topics. The “house” model diagram is one that I use repeatedly to explain strategy plans. It is a simple way to understand the basic elements of successful patient advocacy groups.



At the peak of the roof is CARF’s mission, which is the pinnacle of what we are striving to achieve. The roof needs to be held up by strong pillars, so it does not fall and remains sturdy during all types of weather. The three main pillars for CARF are research, information, and support. Focusing in these three main areas is what drives everything we do, every day. But to hold up these pillars, you must have a strong basement foundation, or infrastructure, which manages the weight

and keeps the pillars straight. Infrastructure includes CARF’s volunteers, fundraising plans, board members, technology, communications tools, etc.

A lot of work has been done in three of the four elements over the past few years, which we have been highlighting in previous newsletters and e-news blasts. We know that more work needs to be done in CARF’s research pillar. The prime culprits are the lack of research funding for scarring alopecia, only a few physician-scientists who study the disease and treatments in their clinics and labs, and little interest from pharma and industry. This is starting to slowly change, and CARF is right in the mix. Because we are the only patient advocacy organization in the world for scarring alopecia, it puts us right in the center of future research because it the patients that are the key.

So, CARF will continue to work hard in 2021 in all the “house” model elements and continue to welcome patients into our organization. We are **engaging young leaders** through the **Medical Student Committee** program (see page 15) and we are adding more virtual support groups (see page 12). We are **launching CARF365** (see page 4) to provide an expanded library of info and resources and will be hosting the **Mane Event Series** (see page 5) to discuss today’s most relevant topics in the scarring hair loss community.

The combination of hair loss discoveries and increased clinical interest, a fast-growing patient population, and strong organizational leadership has placed CARF in a unique position to help and I look forward to our best year yet in 2021!

With warm regards,

*Jean*

Jean Pickford



**SOMETHING GREAT IS GROWING AT  
CARF. WE ASKED. YOU SHARED. WE  
MADE IT HAPPEN! INTRODUCING:**

**CARF365.**  
*Launching January 2021*

#### **What is CARF365?**

CARF365 is CARF's new paid membership program that offers exclusive access to an expanded library of resources only to CARF365 members. CARF365 is the catchy term to signify that CARF is always there with relevant content, information, support, and advice all year long.

#### **What makes CARF365 different than what CARF is doing today?**

To us, everyone is a member of CARF. Belonging to a group that is devoted exclusively to the unique needs of the scarring hair loss community is extremely impactful. That will not change. Everyone will continue to have access to our comprehensive website, support group meetings, e-news blasts, invitations to participate in research, patient outreach volunteer program, and physician referrals. We will continue to host low-cost educational webinars throughout the year and are planning our in-person national conference in 2022. CARF365 is just an expanded library of resources exclusive to those who become sustaining members of CARF through the CARF365 program.

#### **How much does membership cost?**

Membership to CARF is always free. If you would like to be a part of CARF365, the cost is \$48 per year and is billed annually.

**SIGN UP COMING SOON**

#### **What are the benefits of becoming a CARF365 member?**

- A medically focused educational webinar on a specific topic associated with scarring hair loss every two months (6 per year).
- A lifestyle-focused webinar from patients, vendors, or stylists, etc., that features how-to information, techniques, tips and tricks every two months (6 per year).
- Downloadable informational fact sheets and one-pagers to share with your family, friends, physicians, or just keep them to yourself.
- Headlines, CARF's quarterly newsletter, registration discounts to conferences, summits, and webinars.

#### **Why is CARF charging a fee for CARF365?**

CARF is 100% funded exclusively on member donations. By offering an affordable membership option, our hope is to create sustainable revenue so we can continue to support the scarring hair loss community well into the future with consistent programming and resources, and begin to once again fund research.

#### **Do I have to reregister if I am already a CARF member but want to upgrade my membership to CARF365?**

Yes, the CARF365 membership platform is an extension of the CARF website but you will need to register in order to access your account.

## A New Educational Webinar Series Coming Soon!



CARF will be hosting a six-part webinar series throughout 2021. Due to the overwhelming popularity of our virtual webinars last year (see below), the interest in continuing these educational events is in high demand.

The webinars will be 90-minutes long and will feature exceptional speakers and live Q & A. The dates and times are being confirmed this month, so be on the lookout for the official registration and further details in the coming weeks. The webinar topics are listed on the right.

Remember that these virtual live webinars are being taped in their entirety, so if you can't make the actual live events, you will receive the link to watch it on your own.

**The MANE EVENT WEBINAR SERIES**

**February**  
COVID Vaccines & Scarring Alopecia

**April**  
Allergens, Sunscreen & Summer Tips

**June**  
Mental Health & Wellness

**August**  
CCCA, LPP, FFA & All Other Types

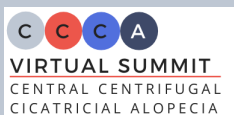
**October**  
Camouflaging, Beauty Products & Services

**December**  
Updates on Research

Bundle of Six Webinars	Yearly Membership	Cost	Total
CARF365 Member	\$48.00	\$180.00	\$228.00
Non-CARF365 Member	\$0.00	\$249.99	\$249.99
Individual Webinars	Yearly Membership	Cost	Total
CARF365 Member	\$48.00	\$35.00	\$258.00
Non-CARF365 Member	\$0.00	\$50.00	\$300.00

**Save With CARF365.**

Take advantage of the savings by becoming a CARF365 member! Save 10% to 16% plus you'll receive all the benefits of CARF365 membership (see page 4).



Click [HERE](#) to purchase the Hair Necessities Patient-Doctor Conference.

Click [HERE](#) to purchase the CCCA Virtual Summit Conference.

If you were not able to attend these live events, you can purchase the taped versions in their entirety. We are proud to offer these timely and educational conferences to the scarring hair loss community.

## UNDERSTANDING END STAGE SCARRING ALOPECIA (ESSA)

BY DR. JEFF DONOVAN, US AND CANADIAN BOARD-CERTIFIED DERMATOLOGIST SPECIALIZING IN THE TREATMENT OF HAIR LOSS, DONOVAN HAIR LOSS CLINIC

End stage scarring alopecia (ESSA) is a term that's often confused. It's a term that pathologists use when describing biopsies of scarring alopecia that are so far advanced that one can no longer tell what kind of scarring alopecia that patient has.

Inflammation is generally no longer present in the specimen so all the valuable diagnostic clues are gone. For example, the pathologist cannot tell if it's lichen planopilaris or discoid lupus or folliculitis decalvans.

They can however tell it's a type of scarring alopecia - but that's where their help ends.

I dislike the term "end stage scarring alopecia" quite a bit because it generally causes more harm than good to many patients with hair loss. So many patients come to see me after losing hair simply because a biopsy told them their disease was end stage. The dermatologist figured that treatment was no longer needed and treatment was stopped. In some cases, treatment was not started because of this result.



A Common Mistake in the Management of End Stage Scarring Alopecia. Let's look together at a very common scenario I see.

**Step 1:** A sample is taken from the scalp and submitted to the pathologist for processing.

**Step 2:** The pathologist looks down the microscope and see massive amounts of scarring and little in the way of inflammation and concludes it's ESSA. Clues are missing. The pathologist assumes inflammation was once present in that area of the skin but now the disease is so far advanced that all clues are gone. Usually the report goes on to say that the disease is end stage and burnt out.

**Step 3:** The dermatologist gets the report and says "Oh my patient's disease is no longer active."

**Step 4:** The patient and dermatologist share in the excitement that treatment is no longer needed because the disease is thought to be burnt out. The patient leaves the clinic and stops medications.

**Step 5:** The patient returns back to clinic in 7 months with more hair loss.

## UNDERSTANDING END STAGE SCARRING ALOPECIA (ESSA)

*Continued from page 6*

### A Very Simple Way to Generate Better Outcomes in The Diagnosis of End Stage Scarring Alopecia (ESSA).

We need to put an end the days when end stage means an end to treatment. This common view is sometimes simply not correct. There is only one way to really know if a patient's scarring alopecia is quiet and inactive and truly burnt out. It's so simple too: a camera! If photos are taken 1 year apart (even better if two years ago) and show no changes in hair density and the patient has no symptoms and the patient's shedding is low and there is minimal redness - the scarring alopecia is likely burnt out.

So here's how the scenario really should play out:

**Step 1:** A sample is taken from the scalp and submitted to the pathologist for processing.

**Step 2:** The pathologist looks down the microscope, sees massive amounts of scarring and little in the way of inflammation and concludes it's ESSA. Clues are missing. The pathologist assumes inflammation was once present in that area of the skin but now the disease is so far advanced that all clues are gone.

**Step 3:** The pathologist generates this report.



*"The histological findings here support a diagnosis of advanced scarring alopecia. The pathological findings in the current specimen that was submitted are advanced to such a degree that it is not possible to differentiate this scarring alopecia into a specific subtype type (lymphocytic, neutrophilic, etc.). This has traditionally been called end stage scarring alopecia in the past. Clinicopathological correlation is needed to accurately determine if these histological findings actually imply inactive disease (ie: so-called "burnt out scarring alopecia") or whether the patient may in fact have ongoing and progressive hair loss in this or other areas of the scalp. The clinician is advised to take note that histological findings of end stage disease may not always correlate with the patient's disease truly being burnt out. Close monitoring is advised."*

**Step 4:** The dermatologist gets the report and says "Oh, my patient's disease seems end stage - I'm going to follow him or her closely and see if this is what's really happening in the scalp or not"

**Step 5:** The patient and dermatologist review the unknowns of ESSA. Photos are taken before leaving, with a plan for the patient to return in a defined period. The patient may or may not continue treatment.

**Step 6:** The patient returns back to clinic in a defined period for review of photos, symptoms and signs.

**Step 7:** A decision is made with the clinician as to whether the scarring alopecia really is "burnt out."

## HYDROXYCHLOROQUINE USE AND COVID-19 CONCERNS AMONG ALOPECIA PATIENTS: A CROSS-SECTIONAL SURVEY STUDY

*Continued from page 1*

cicatricial alopecia during COVID-19 including infection with SARS-CoV-2, treatment concerns, and medication access.

An email survey was distributed to 5,103 Cicatricial Alopecia Research Foundation (CARF) members in July 2020 as a link within a newsletter. The survey was limited to those who had a formal diagnosis of cicatricial alopecia. Those considered taking HCQ had to report use for at least six consecutive months. A total of 626 individuals interacted with the survey link in the newsletter and a total of 165 surveys were completed, representing a response rate of 3.23% of those who received the newsletter and 26.4% of those who interacted with the link. Respondents were grouped by HCQ and non-HCQ (NHCQ) treatments. Nine HCQ participants failed to meet minimum therapy duration and were excluded. The average daily HCQ dose was 312.7 mg (57-600 mg) and the average therapy duration was 2.92 years (0.5-15 years). There were no significant differences in demographics including geographic region, diagnoses, or underlying conditions between the groups (Table 1).

Concern regarding access to medications was greater among the HCQ group ( $P = .002$ ), with 16% rating their concern at least 70 of 100 vs 5.4% of the NHCQ group. COVID-19 led to interrupted HCQ therapy in two respondents. Three NHCQ patients (3.8%) requested to start HCQ due to COVID-19. Our study failed to identify a significant relationship between long-term HCQ treatment and COVID-19 infection. A



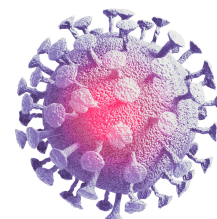
### MEDICAL & SCIENCE

significant number of NHCQ patients reported fever since December 2019 (Table 2). However, the small sample size of our study and low COVID-19 testing volume preclude valid comparison of incidence and infection between the groups.

Patients on long-term HCQ for hair loss had greater anxiety about therapy interruption, but only 3.8% reported experiencing interruptions. However, patients taking HCQ may experience future interruptions. The literature examining the efficacy of HCQ against COVID-19 infection is mixed. The potential for increased prescription of HCQ during the COVID-19 pandemic could create drug shortages. While there is a real potential for drug shortage, dermatologists can counsel concerned patients taking long-term HCQ that there have been few reported interruptions to date. In the event of increased HCQ use against COVID-19, drug production efforts should account for patients on chronic therapy to minimize treatment interruption.

*\*Cross-sectional - A cross-sectional study is defined as a type of observational research that analyzes data of variables collected at one given point in time across a sample population or a pre-defined subset. This study type is also known as cross-sectional analysis, transverse study, or prevalence study.*

*\*\*Immunomodulatory effects - drugs modify the response of the immune system by increasing (immunostimulators) or decreasing (immunosuppressives) the production of serum antibodies.*





## HYDROXYCHLOROQUINE USE AND COVID-19 CONCERNS AMONG ALOPECIA PATIENTS: A CROSS-SECTIONAL SURVEY STUDY

Continued from page 8

Table 1. Characteristics of Alopecia Patients

Category	Hydroxychloroquine (n=53)	Non-Hydroxychloroquine (n=101)	P value
<b>Age, mean ± SD</b>	63.9 ± 8.3	61.1 ± 11.1	0.11
<b>Race, Ethnicity, or Origin, n (%)</b>			
American Indian or Alaska Native	0 (0.0%)	1 (1.0%)	
Asian or Pacific Islander	1 (1.9%)	0 (0.0%)	
Black or African American	0 (0.0%)	8 (7.9%)	
Hispanic or Latino	0 (0.0%)	0 (0.0%)	
White	51 (96.2%)	91 (90.1%)	
Other	1 (1.9%)	1 (1.0%)	
<b>Sex, n (%)</b>			
Female	49 (92.5%)	96 (95.0%)	
Male	4 (7.5%)	5 (5.0%)	
<b>Alopecia Diagnoses, n (%)</b>			
Lichen planopilaris (LPP)	13 (24.5%)	22 (21.8%)	0.15
Frontal fibrosing alopecia (FFA)	19 (35.5%)	35 (34.7%)	0.14
Both LPP/FFA	10 (18.9%)	16 (15.8%)	0.16
Alopecia mucinosa	0 (0.0%)	3 (3.0%)	0.28
Multiple cicatricial diagnoses <sup>†</sup>	5 (9.4%)	8 (7.9%)	0.22
Central Centrifugal Cicatricial	5 (9.4%)	11 (10.9%)	0.21
Graham - Little Syndrome	1 (1.9%)	0 (0.0%)	0.34
Dissecting Cellulitis/Folliculitis Decalvans	0 (0.0%)	2 (2.0%)	0.43
Other	0 (0.0%)	3 (3.0%)	0.28
<b>Underlying Conditions, n (%)</b>			
Asthma	6 (11.3%)	14 (13.9%)	0.18
Emphysema or COPD	1 (1.9%)	1 (1.0%)	0.45
Diabetes	2 (3.8%)	3 (3.0%)	0.34
Rheumatoid Arthritis	1 (1.9%)	2 (2.0%)	0.45
Current Tobacco Use	0 (0.0%)	2 (2.0%)	0.43
<b>U.S. Region<sup>‡</sup>, (n%)</b>			
Northeast	27 (57.4%)	57 (60.6%)	1.00
Midwest	4 (8.5%)	6 (6.4%)	
South	6 (12.8%)	11 (11.7%)	
West	10 (21.3%)	20 (21.3%)	

<sup>†</sup> includes combination of cicatricial disease other than concomitant diagnosis of lichen planopilaris (LPP) and frontal fibrosing alopecia (FFA). <sup>‡</sup> No data/Non-US participants (6 HCQ, 7 Non-HCQ) not included in regional analysis.

Table 2. Characteristics of COVID-19 Among Alopecia Patients

Category	Hydroxychloroquine (n=53)	Non-Hydroxychloroquine (n=101)	P value
<b>COVID-19 testing, n (%)</b>			
Total tested	2 (3.8%)	8 (7.9%)	0.18
Positive test	0 (0.0%)	0 (0.0%)	1.00
Negative test	2 (3.8%)	6 (5.9%)	0.27
Unknown result	0 (0.0%)	2 (2.0%)	0.43
<b>New symptoms since Dec. 2019, n (%)</b>			
Two or more symptoms	3 (5.7%)	15 (14.9%)	0.07
<b>Fever<sup>‡</sup></b>	1 (1.9%)	12 (11.9%)	<b>0.02</b>
Cough	5 (9.4%)	15 (14.9%)	0.13
Dyspnea	3 (5.7%)	6 (5.9%)	0.28
Pleuritic chest pain	1 (1.9%)	4 (4.0%)	0.32
Diarrhea	3 (5.7%)	5 (5.0%)	0.28
Anosmia	2 (3.8%)	2 (2.0%)	0.31
Myalgias	2 (2.8%)	7 (6.9%)	0.22
Sought medical care for symptoms	6 (11.3%)	11 (10.9%)	0.21
<b>Exposure, n (%)</b>			
Known exposure to COVID-19	1 (1.9%)	5 (5.0%)	0.26
Leaving home for work	10 (18.9%)	16 (15.8%)	0.16
Immunosuppressive therapy	1 (1.9%)	5 (5.0%)	0.23
Outside U.S. since December 2019	8 (15.1%)	12 (11.9%)	0.17
Use of at least 1 "social distance" measure	53 (100%)	101 (100%)	0.10
<b>Concerns (stress) due to COVID-19 (0-100), average<sup>†</sup></b>			
<b>Stress due to COVID-19<sup>†</sup></b>	48.1	56.4	<b>0.02</b>
Becoming Infected with COVID-19	55.6	58.3	0.50
<b>Changes to Medications due to COVID-19<sup>†</sup></b>	34.8	20.8	<b>0.002</b>

<sup>†</sup> Participants asked to rate stress/concern with a score of 0 being "no stress" and a score of 100 being "worst stress imaginable". <sup>‡</sup> Statistically significant.



## MEET OUR NEW BOARD MEMBERS

In December, CARF's Board of Directors elected three new members and four new Medical and Scientific Advisory Board members to join our dedicated group of leaders. CARF is beyond grateful to have such generous, knowledgeable advocates on our team!



Crystal Ugochi Aguh, MD  
Johns Hopkins University



Jeffrey Donovan, MD  
The Donovan Hair Clinic



Andrea Furgala, LISW-CP  
Child & Family Therapist



Ronda Farah, MD  
University of Minnesota



Jamie MacKelfresh, MD  
Emory University



Natasha Mesinkovska, MD, PhD  
University of California, Irvine



Melissa Piliang, MD  
The Cleveland Clinic



### Executive Board

Rita Wanser, President  
Kris Wharton, President-Elect  
Wilma Bergfeld, MD, VP  
Christine Janus, Treasurer  
Maryanne Senna, MD, Secretary

### Board Members

Crystal Aguh, MD  
Andrew Alexis, MD  
Lorraine Bernstein  
Jeff Donovan, MD  
Andrea Furgala  
Elise Olsen, MD  
Maria Hordinsky, MD  
Yolanda Lenzy, MD  
Jim O'Connell

### Medical & Scientific Advisory Board

Victoria Barbosa, MD  
Valerie Callender, MD  
Angela Christiano, PhD  
Ronda Farah, MD  
Lynne Goldberg, MD  
Cory Hartman, MD  
Loren Krueger, MD  
Jamie MacKelfresh, MD  
Amy McMichael, MD  
Natasha Mesinkovska, MD, PhD  
Paradi Mirmirani, MD  
Apostolos Pappas, MD  
Melissa Piliang, MD  
Nicole Rogers, MD  
Jerry Shapiro, MD  
Kumar Sukhdeo, MD, PhD  
Ken Washenik, MD



## FUNDRAISING & AWARENESS

### Easy Automatic Funding

#### [Shop with Scrip](#)

Scrip fundraising allows members to support CARF by using gift cards for their everyday shopping.

#### [GoodShop](#)

When using this shopfunding site, choose Cicatricial Alopecia Research Foundation and shop as you normally would online. A percentage of what you spend will be donated to CARF - it's that simple!

### Support CARF While You Shop



#### It's as easy as 1,2,3.

1. Open the Amazon Shopping app on your device. Go into the main menu of the Amazon Shopping app and tap 'Settings'
2. Tap 'AmazonSmile' and follow the on-screen instructions to complete the process
3. If you do not have the latest version of the Amazon Shopping app, update your app.

CARF receives a donation for every eligible purchase. CARF received \$1,737.18 as of November 1st, 2020. What can we raise in 2021?



CARF's *Be a Matchmaker* campaign provided a vehicle for members to double their donations through a major donor match. CARF is excited to report the *Be a Matchmaker* campaign donations totaling \$19,000 were doubled to \$38,000. CARF is incredibly grateful. Your generosity is truly humbling and inspiring. Our hearts are full of gladness and thanks. Your support will help change the lives of CARF members today, tomorrow and beyond.

### Rare Disease Day: Feb 28 #LetsGetVisible



Did you know that scarring hair loss is categorized as a rare disease? CARF is asking our members to help raise awareness of scarring hair loss by participating in Rare Disease Day on February 28, 2021. Contact CARF [HERE](#) if you are willing to share your story or to submit a myth about scarring hair loss you'd like to dispel. Be sure to keep an eye out for additional opportunities to help raise awareness and support for the scarring hair loss community in our #LetsGetVisible campaign.



## SUPPORT GROUPS

CARF is committed to launching 10 new support groups in 2021! Join the movement and start a group in your state. Contact CARF at [info@carfintl.org](mailto:info@carfintl.org) with questions or to become a Support Group Volunteer Leader.

“Being around other people just like me in a safe, welcoming group setting is not only therapeutic, it's life-changing.”



Click [HERE](#) to register for the next support group meeting near you. You only need to register ONCE to receive future notifications.

### Atlanta Virtual Support Group

Date: January 25, 2021 at 7PM

Save The Date: April 26, July 26 & Oct. 26

### Boston Virtual Support Group

Date: April 25, 2021 @ 2:30PM

Save The Date: Sept 26 & Jan 9

### CCCA USA Virtual Support Group

Date: February 21, 2021 @ 7PM

Save The Date: March 31 & April 18

### Chicago Virtual Support Group

Group Leader Needed

Contact Colleen [HERE](#)

### Dallas Virtual Support Group

Date: April 10, 2021 @ 2PM

Save The Date: July 10 & October 9

### Maryland Virtual Support Group

Date: April 14, 2021 @ 7:30PM

Save The Date: July 14 & October 13

### Michigan Virtual Support Group

Date: April 13, 2021 @ 7:30PM

Save The Date: July 13 & Oct. 12

### New Orleans Virtual Support Group

Date: April 11, 2021 @ 3:00PM

Save The Date: July 11 & October 10

### NYC Virtual Support Group

Date: January 26, 2021 @ 7PM

Save The Date: April 27, July 27 & Oct. 26

### San Francisco Virtual Support Group

Date: April 6, 2021 @ 5:00PM

Save The Date: July 6 & October 5

### Tampa Virtual Support Group

Date: April 24, 2021 @ 10:00AM

Save The Date: July 17

### CCCA UK Virtual Support Group

Date: April 13, 2021

Save The Date: July 13 & October 12



## MEET OUR MEMBERS

### **Claudia Cashman - Actor. Singer. Dancer. Radio Voice. A woman of many talents.**



If someone asked me to describe myself in five words, they would be compassionate, creative, funny, intellectual, and curious. I really am an introvert, but an egregious introvert. My best talent is thinking outside the box and finding creative solutions to problems. But when I was diagnosed with Frontal Fibrosing Alopecia (FFA), it knocked me back a bit.

It was about 12 years ago when I noticed my first signs of hair loss. I noticed a difference in my hair and scalp and thought it might be dandruff or something minimal, so I waited for about two years before seeing a specialist. I was diagnosed with a chronic, autoimmune

disease but never in my wildest dreams did I think it would be a permanent hair loss condition. To me, it literally came out of left field.

Once I had my official diagnosis, I learned about the different medications and treatments that were available. It was my personal choice not to take any of them. My thinking was that I would not be better off if I did, because nothing is guaranteed to stop the progression. So, I opted to let it run its natural course.

I felt like the rug was pulled out from underneath me. My thoughts focused on losing all my hair, and how it was going to change my life. I could not swim in public anymore or go on a boat. How do I hide this? I would get very depressed and I gave into that. Fortunately, I was able to get more into my artwork and it kept me going. It took a while, but I eventually got over telling people about it, and came to accept it.

It took about a full five years for it to do its thing. All my hair is gone up to the top of my head and what hair I have left is curly. In 2018, I attended the CARF Patient Conference and it was pretty fabulous. I do have to admit that I felt somewhat like an imposter because, at the time, I still had a lot of hair.

What I have learned during this 9-year journey is that it is a slow process. It doesn't happen at all once and that is a good thing because there are so many places and resources to seek support. The hair loss progression gives you time to adjust and accept it. However, when I show family, friends, and others my FFA, it still bothers me to see the reaction in their faces.

## **Claudia Cashman - Actor. Singer. Dancer. Radio Voice. A woman of many talents.**

*Continued from page 13*

Everyone is always polite and kind in what they say, but I can see the shock and surprise written on their faces. Right now, the worst part of having FFA is that my forehead still burns and itches. My hair specialist is done with me. She says, "If you're not going to take the drugs, then there is no point in coming back." I also have a big fear that someday I will be in a car accident and the responders will pull my hair back and look at me with shock. I would feel embarrassed.

Having FFA does have its positive moments, though. It has inspired more creativity in me as an artist and photographer. I even started doing selfies and look at them and think, "I wouldn't look that bad bald." It has made me look at myself differently and readjust in a different direction. My confidence has increased, and I have more resilience. It definitely has caused my perspectives to change.

I have found that sleeping with a silk pillowcase helps a lot and I generally do not touch the hair I have with my fingers. I just plump it with a brush. I like having good hair days at home. I switch up shampoos a lot to keep my hair moisturized and I still color it. I wash my hair a couple times per week, depending on the way my curls form. It is an emotional ordeal, and I still get a little depressed when I must wash.



If I had an extra week off from work, where I could go somewhere by myself, it would be a little cabin in the woods with a nearby stream. I would not have to worry about anyone seeing me. There would be a fire in the fireplace, and I would be taken care of by the universe. There would be a big platform in the middle of a field with a full moon shining on me. I would be able to dance again with music and relax from the judgement.



**We would love for you to share your story with CARF members. Sometimes just sharing or reading about how others cope with their hair loss can be just the thing you need. Contact CARF at [info@carfintl.org](mailto:info@carfintl.org) to share today!**



## NEWS & NOTES

### CARF VOLUNTEERS NEEDED

CARF is always excited when a member contacts us asking how they can get involved. Interested in sharing your talents with CARF? Click [HERE](#) to get in touch. We can't wait to hear from you!



### CARF MED STUDENT PROGRAM

CARF is excited to share we will be launching a Med Student Program soon.

This program will host 6 committees: education and awareness, support groups, communications, dermatological programs, fundraising and advocacy.

CARF will recruit medical students from dermatological programs across the US and around the world to create greater awareness and understanding of scarring hair loss.

### THERAPIST REFERRAL LISTING

CARF members have requested help in finding therapists who work with individuals with scarring hair loss. If you have a therapist you would like to recommend, please click [HERE](#) and submit their information so it can be shared with the CARF community.

## Quality of Life and Resilience in Patients with Cicatricial Alopecia: A Cross-Sectional Study

**Dr. Maryanne Senna, a Harvard-affiliated dermatologist and hair loss researcher who recently presented at CARF's Hair Necessities Virtual Conference, is interested in learning more about a possible connection between your quality of life and resilience related to your hair loss.**

**Dr. Senna and her study team have created an online survey and welcome your participation. The survey study is optional and your identifiable information will not be tied to your survey answers.**

**If you are (1) over the age of 18 years old and (2) have been diagnosed with scarring alopecia, you are eligible to complete the survey. To complete the survey, please click the link in the comments.**

**Click [HERE](#) to participate. If you have any questions about the research survey, please e-mail [MGHHAIR@partners.org](mailto:MGHHAIR@partners.org).**