

HEADLINES

The Official Newsletter of the Cicatricial Alopecia Research Foundation

March 2020 Vol.31



A Summary on Latest Frontal Fibrosing Alopecia Research Involving the JAK-STAT Pathway

By Laura J. Burns, BS Research Fellow; Edited by Dr. Maryanne Senna

Frontal Fibrosing Alopecia (FFA) is a type of scarring alopecia with increasing incidence and currently no effective treatments. Little is known about what causes the disease. This study identified the type of immune cells in FFA compared to healthy patients and also to patients with alopecia areata (AA). The researchers identified an increase in one immune pathway of inflammation, called the JAK-STAT pathway, which can be targeted by medications currently in testing for AA. These medications are known as JAK inhibitors. Examples include tofacitinib (Xeljanz) and ruxolitinib (Jakafi).

Scalp biopsies in patients with active FFA show a robust number of immune cells

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Foundation (CARF).

HEADLINES is published
quarterly by CARF. Requests to
reprint information contained in
Headlines should be directed to
the editor.

CARF
1586 Sumneytown Pike
PO Box 1322
Kulpsville, PA 19443
Phone: 267.613.9811
Email: info@carfintl.org
www.carfintl.org

Executive Director
Jean Pickford

Editor
Colleen Leader

Medical Editor
Jamie MacKelfresh, MD

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CARF
CICATRICIAL ALOPECIA
RESEARCH FOUNDATION



CORRESPONDENCE CORNER

Hi everyone,

Godiva's Secret Wigs: Their wigs are synthetic and are truly beautiful. You can order online and shipping is fast. You can also return your purchases if you aren't happy with your style or color choice. Losing my hair has been relatively trauma free because I now have "hair" that is much nicer than what nature gave me.

~**Suzanne Y., CARF Member**

Dear Friends,

Toppik Hair Fibers: Hair fibers are great for camouflaging the scalp when hair is thinning, particularly on the top. I found Toppik easy to use – like using a salt shaker – which took all the guess work out. It's also easy to shampoo out and it comes in a variety of colors, too. This tool was a great help to me when I became very self-conscious of my scalp visibly showing.

SEEN Shampoo & Conditioner: I LOVE SEEN! I've scoured products trying to find a great shampoo and conditioner that didn't have chemicals to further damage my already sensitive scalp and skin. SEEN met those requirements and then some. It cleans and conditions my hair beautifully without the worry of further harming my hair or skin.

– **Kris W., CARF Board Member**





BY RITA WANSER
CARF PRESIDENT

2019 Annual Report

Dear Members, Friends and Donors of CARF,

At this time of year, I enjoy reflecting over the past year of CARF's accomplishments and highlighting them for you. It reinforces in me the goodness in people and how very important advocacy and outreach is to those in need of a voice, information and education on a very personal issue. CARF remains the leading organization for information about cicatricial alopecia worldwide.

As I think about our great organization and accomplishments, my first thought is "What a difference a year makes!" To me, the growth in CARF's abilities is just as important as a quantifiable achievement, which has been clearly demonstrated with our most recent response to the COVID-19 pandemic. Jean continues to deliver for you, and has helped CARF become agile. This was clearly demonstrated when CARF received many inquiries from concerned members regarding their condition and the coronavirus. Within one week of this massive global crisis, we responded to all these inquiries and provided an online educational webinar hosted by Dr. Maryanne Senna explaining in a concise and understandable way how COVID-19 impacts those with scarring alopecia. In less than 12 hours of hosting the live webinar, it was seen by over 1850 viewers on Facebook and YouTube combined.

These expanding abilities are helping CARF's outreach to not only current members, but those who are newly diagnosed or isolated. CARF is now on Facebook, LinkedIn, Instagram and YouTube, creating further awareness and reaching so many more people.

Technology has not been the only area of growth for CARF. An eager group of medical students and young physicians have joined the CARF team and are very active.

They've become involved with the 2020 patient conference planning, the upcoming roll out of support groups and meetings, guidance about ways to improve our technology, and interpreting medical literature to share on the website in an easy-to-read format.

CARF's fundraising has gained some strength too. A big push at the end of the year to match two \$10,000 gifts was met with resounding success! Our membership and friends matched these gifts in record time and put CARF in a stronger financial position to start the new year. We also had the honor and privilege to recognize one of CARF's founders, Dr. Vera Price, at a testimonial dinner among her family, friends and peers. It was special in so many ways and resulted in \$20,000 to support CARF.

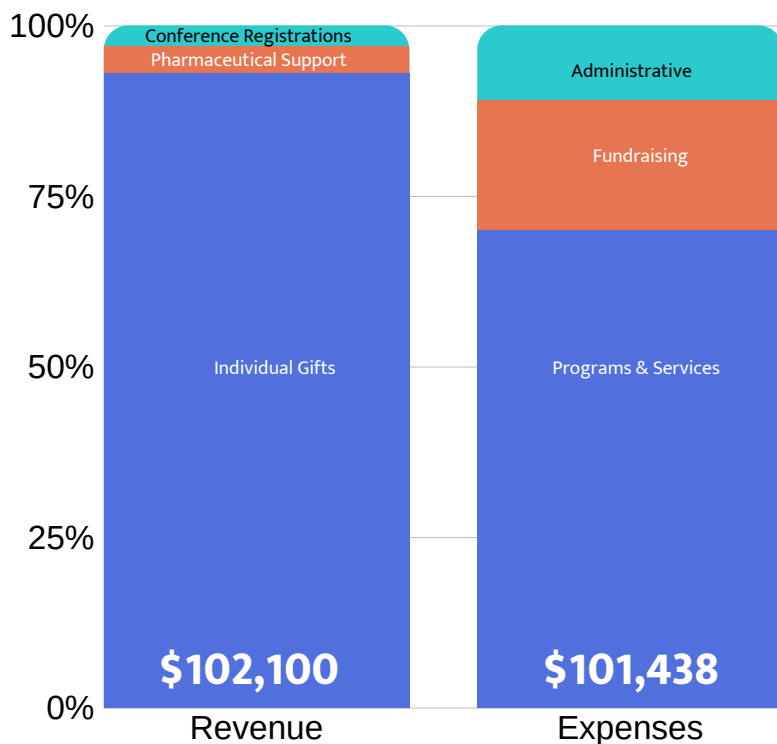


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Annual Report Continued

Last year, CARF's revenue totaled of \$102,100, with the majority of funds raised from a small group of 230 individual donors. The balance was comprised evenly between pharmaceutical support and conference registrations. Approximately 70% of monies raised last year were allocated for CARF's programs and services and the remaining was split between fundraising and administrative fees.

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Approximately 70% of monies raised last year were allocated for CARF's programs and services and the remaining was split between fundraising and administrative fees.

It is heartwarming that we have such dedicated and generous donors. What we need from the rest of our members is to grow our donor base. Our staffing is limited because of lack of money. Imagine how much more could be done if we could increase the hours of our current part-time staff? We have a population of over 5000 patients in our database, so please actively participate in our growth with your financial support.

We are connected and actively work with THE subject matter experts in cicatricial alopecia. What does that mean for you? You have the support from these doctors, as they extend their knowledge, research and support beyond their own patient population. They give freely of their time and talent to support CARF activities and patients, despite their busy schedules and personal and professional obligations. I am so grateful and in awe of their work with patients, research and the CARF community and CARF is better because of them!

Sincerely,

Rita Wanser

Annual Report Continued

**Thank you to our many wonderful donors and supporters of CARF.
We may be a small, but we are MIGHTY!**

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\$2500+

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NEW DATE

CONFERENCE RESCHEDULED

November 20 - 22

ONLINE REGISTRATION OPENS ON JUNE 1
Hilton Nashville Airport Hotel

Registration Fee - The registration fee covers the hotel's costs for (7) meals and (4) breaks. CARF does not collect additional fees from registrations; it is strictly the cost of your meals while attending the conference. Other meeting expenses are supported by generous donations and sponsors. Registration opens June 1 – November 9, 2020 - \$400.00 pp.

Hotel Room Reservations - The hotel room contract is being finalized and CARF will post the direct link to reserve rooms at the Hilton Nashville Airport Hotel soon. Please note, all room reservations will be on a first come first served basis.

Meeting Agenda - The meeting agenda is set and will remain very close to the original agenda. Conference attire is casual.

Airport Information & Shuttle - The Nashville International Airport (BNA) is located just two miles (five minutes) from the hotel. There is a complimentary shuttle from the BNA Airport that runs 6:00 am – 11:00 pm daily.

About the Hilton Nashville Airport - Set in Historic Mud Tavern and just down the road from Opryland, the Hilton Nashville Airport hotel is minutes from popular local restaurants, famous concert venues, shopping malls, golf courses, lush city parks and family-friendly attractions. Along with the hotel's convenient airport access, they offer a shuttle service for a nominal fee to see downtown Nashville's popular attractions. [CLICK HERE](#) to learn more about Nashville and its attractions.

Optional Friday Night Outing - Join your fellow conference attendees on a guided bus tour around Music City, see where the Music is Made on historic Music Row, travel through Centennial Park past the Parthenon, and cruise down Honky Tonk Row. The guide will share the story of Nashville throughout the tour. Then, enjoy a true Southern meal at one of Nashville's most beloved family owned restaurants, The Hermitage House Smorgasbord.



MY STORY: Finding the Answers

BY ADRIENNE DAVIS-BRODY

My story is probably much like most of yours. I started noticing hair thinning at age 66. I wasn't overly concerned since I always had a full head of hair. I asked my hair stylist what she thought, and she said that's typical of women my age.

Strangely, I wasn't seeing clumps of hair falling out or abnormal shedding but clearly my temporal hairline and side-burn area were receding; my eyebrows were thinning; and my body hair had already disappeared. So much for the joy of not having to shave my legs and arm pits.

Being a person of action, I made an appointment with my dermatologist. As luck would have it, I got to the right person at the right time. My dermatologist, Dr. Laurel Morton at SkinCare Physicians in Chestnut Hill, had done her residency with Dr. Lynne Goldberg, one of the country's leading researchers in hair loss. Dr. Morton agreed something was going on and insisted that Dr. Goldberg read my biopsy. I can't stress enough that finding the right doctors is the key to getting on the right track. I hear of too many missteps and lost years, frustration and depression, in people's quest to find the answers. Although the biopsy was inconclusive, Dr. Morton prescribed Clobetasol, Minoxidil and Doxycycline. I was freaking out. I realized that my hair was my shield against the world. It was part of my self-image. As a Leo, it was my mane. I was queen of the jungle.

I surfed the Internet and found CARF and



was referred to a volunteer in Colorado. The volunteer patiently explained the disease and all drugs that people were trying. Honestly, I was even more confused and depressed. FFA and LPP were letters in the alphabet and I didn't know where to turn for comfort and advice.

I quickly joined the amazing group of people going through what I was going through on the Facebook page – Let's Put out the Fire.

My research did not stop there. I was on the wait list to see Dr. Lynne Goldberg at Boston City Hospital and Dr. Maryanne Senna at Mass General Hospital. In addition, I went to New York City and was seen by Dr. Jerry Shapiro at NYU Langone Medical Center who concurred with the biopsy and the drugs that I was taking. Little did I know at the time that all three amazing physicians are actively involved with CARF.

Fast forward four years. Yes, I still freak out and have bouts of depression and sleepless nights, but I know in my heart of hearts, I am doing everything humanly possible to find answers. I stay on the forefront of all new protocols like PRP (Platelet Rich Plasma injections), micro-needling, and new medications. Most importantly, I am open about my condition in hopes that I can help someone else.



MEDICAL & SCIENCE

Continued from page 1

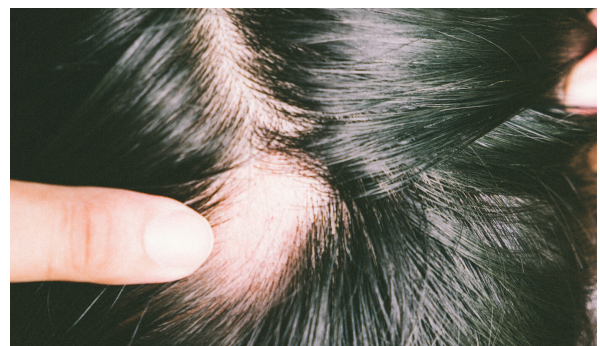
causing inflammation, and these cells are centered at the middle part of the hair follicle. This area of the hair follicle is known as the bulge and is where the hair follicle stem cells reside. With time, these stem cells are destroyed and scar tissue, or fibrosis, develops. However, microscope images cannot classify the types of immune cells or the active cellular signaling pathways as well as specialized studies called gene expression studies. Gene expression studies can unlock this information and allow for more targeted treatment approaches, and that is the type of study used in this research paper.

This type of research has been conducted in alopecia areata, a non-scarring, inflammatory hair loss disorder. By classifying increases in immune cells and hormonal signalers, scientists have tested novel therapeutics, such as JAK inhibitors, demonstrating remarkable efficacy in early clinical trials. Preliminary studies show that FFA and AA share similarities in inflammatory fingerprints, but at different locations within the hair follicle unit. Here, investigators aimed to examine this relationship and possibly reveal similar treatment potential for FFA.

In this study, 12 patients with FFA, 8 patients with AA, and 8 healthy controls were tested.

Researchers examined biopsies under the microscope and gene expression signatures. The highlighted results are as follows:

- Significant immune abnormalities were present in active FFA and AA. Specifically, CD8+ cells in FFA were increased at the hair bulge compared to healthy control patients.
- Th1 cytokines were increased in FFA. Th1 cytokines are pro-inflammatory signalers. They recruit destructive types of immune cells. Like a fire alarm that triggers sprinklers, emergency personnel, and spectators, Th1 cytokines attract a variety of cells that drive inflammation.
- The JAK3 pathway also showed increased expression in FFA. This is just one of the many JAK-STAT pathways that have been identified and targeted by various new medications. JAK3 is closely linked to the production of Th1 cytokines. When there is more JAK3, it leads to more Th1 cytokines and subsequently more inflammation.
- Stem cell markers were found to be diminished but still present in scalp affected by FFA, suggesting that regeneration of hair follicles may be possible if inflammation is decreased.



Continued from page 8

Taken together, these findings suggest a prominent Th1 / JAK-STAT pathway in FFA, which is similar to that of AA. Despite small sample size and limitations in gene testing, the data indicate potential for treating FFA with targeted JAK-STAT medications, either orally or topically. Modulating this pathway will decrease downstream Th1 cytokine production and subsequent inflammatory cell recruitment. Although further studies are warranted, this research reveals exciting new insight into the cellular mechanisms driving FFA and promising new treatment approaches.

A layman's summary of the most recent article first published on March 25 in the British Journal of Dermatology entitled Frontal Fibrosing Alopecia shows robust Th1 and JAK3 skewing by E. Del Duca J. Ruano Ruiz A.B. Pavel R. Dutt Sanyal T. Song J. Gay-Mimbrera N. Zhang Y.D. Estrada X. Peng Y. Renert-Yuval R.G. Phelps R. Paus J.G. Krueger E. Guttman-Yassky. [Click here](#) to read the full article.

Volunteers are the heart of CARF. There are a variety of ways you can make a difference.

- No amount of time is too small.
- Fundraise by hosting an event or creating a Facebook donation page.
- Connect with others by becoming a Patient Outreach Volunteer.
- Inspire others by sharing your story.
- Share products and services that have made a difference in your scarring alopecia journey.
- Share your professional skills.
- Medical professionals can join one of our working groups.

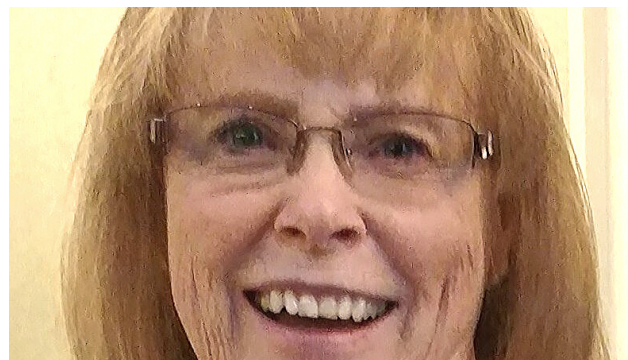
Our CARF office is very small, but thanks to the willingness and generosity of our volunteers, we can expand our reach in the cicatricial alopecia community.

Patient Outreach Volunteer Highlight: Marilyn Ey

When I was diagnosed with cicatricial alopecia, a CARF volunteer reached out to me. After our phone conversation, I cried tears of joy because I knew I was no longer alone. When CARF received a request from another member to connect her with an FFA patient, CARF asked me to support this member. She and I spoke many times, became friends, and met and hugged each other at the very next CARF conference. That was how I became a CARF POV (Patient Outreach Volunteer) and I continue to serve in this role still today!

I've connected with people from all over the world. In the process they've shared what helps them deal with their hair issues. Wow, are cicatricial alopecia patients creative and resourceful! At the upcoming Nashville conference, Nancy (another POV) and I will share tips and tricks with you. For example...for inflammation, heat is bad, cold is good. When first

diagnosed, I asked myself, "Why me?" Why did I get cicatricial alopecia? Why do I have to suffer? Learning to cope with itching, burning, hair loss, depression, frustration, and feeling alone helped with relating to others. By sharing stress reduction techniques, mini hair piece information, inflammation reducing tricks, etc., your journey to hair peace is an easier path. Interested in connecting with a POV? [CLICK HERE](#). We look forward to hearing from you!





FUNDRAISING

Your Invitation to Join CARF's New Gem Club

CARF will be inviting everyone in the scarring alopecia community to join its new Gem Club next month! Gem stands for Gives Every Month through our easy 'set-it- and-forget-it' automated monthly recurring donation campaign. Our goal is to secure a combination of 135 gems at the levels below:

Diamond - \$100.00 per month (\$1200 per year)

Ruby - \$50.00 per month (\$600 per year)

Sapphire - \$25.00 per month (\$300 per year)

Emerald - \$10.00 per month (\$120 per year)

Easy Automatic Funding

[Amazon Smile](#)

Every time you shop on Amazon Smile, CARF will receive a small percentage of your purchase at no cost to you! You **MUST** shop through the smile.amazon link for Cicatricial Alopecia Research Foundation to receive a donation. Bookmark the link above!

[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!

Grassroots FUNDRAISING

Have you ever wanted to do some fundraising to help CARF but either didn't have enough time in your day or were too nervous to ask people for money? We've got you covered!! CARF has a list of fundraising ideas that range from super easy to more involved, and from indirect solicitations to face-to-face direct requests for support. Whether you are personally affected with scarring alopecia or simply want to show your support of a friend or loved one, we've got some great ideas for you to either jump right in or spark your creativity to host your own original fundraiser. Here are just a few to get you thinking:

- Facebook Fundraiser
- Matching Gifts
- In Lieu of Gifts
- United Way
- Restaurant Night Out
- Wine Tasting
- 50/50 Raffle
- Garage Sale
- It Makes Cents Drive
- Auction

Email Jean or Colleen at the office to explore ideas at info@carfintl.org.



SUPPORT GROUPS

HOW TO START A GROUP:

It's as easy as 1, 2, 3!

1. Email your location and contact info.
2. We will reach out to discuss the specifics (type of meeting, date, time, location, etc.).
3. CARF will list the meeting on our website and email local members to share the details.

That's it! Contact us today and let's create a support group in your area!

CARF is happy to offer two options for member support gatherings!

1) CARF Patient Support Group

- Requires a Medical Advisor
- At least 1 Patient Volunteer Leader
- Program and or formal agenda
- Meets 2-4 times per year

2) CARF Connects Networking

- At least 1 Patient Volunteer
- Meets 2-4 times per year
- Socialize and connect organically

Both groups need to secure a space to meet, collect contact info from the group, and provide the leader and medical advisor information to CARF so we can add your group's info to our website.

CARF SUPPORT GROUPS

- Boston Support Group
- New Orleans Support Group
- San Francisco Support Group
- Denver Support Group
- New York City Support Group
- Dallas Support Group
- Chicago Support Group
- Tampa Support Group

[CLICK HERE](#) to view groups on the CARF website.



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



FROM THE DIRECTOR



Dear Members and Friends of CARF,

The first quarter of this year has certainly been an eventful one for CARF. It has mimicked a roller coaster ride, with ups, downs, and ups again! We've packed a lot into the last three months and I'm proud to share this update with you.



CARF experienced some personnel changes with the departure of Madeline Miller. Some of you may have had a chance to meet Maddy in person at the Philly conference, or talked with her over the phone or corresponded through email. Congratulations are in order as Maddy's family expanded once again with the birth of her second son, Colby William, on March 5th. Colby joins his big brother, Caleb. Maddy has stepped away from CARF to devote more

time to her little ones. Maddy worked closely with me for the past two and a half years. She has been an integral part in growing CARF and loved serving our members. She is a treasure to CARF and will be missed very much.



I'm excited to introduce Colleen Leader, our newest addition to the CARF team. Colleen has an extensive background in marketing and communications and has jumped right in with both feet! She's already ramped up our social media presence in just the eight weeks she's been on board! You can look forward to meeting and interacting with Colleen as we work closely together to serve patients and advance CARF's mission.

I am also excited to introduce several new members to CARF's governing Board of Directors. Lorraine Bernstein and Kris Wharton, two long-time CARF members were nominated and stepped into leadership roles this past January. They certainly earned some stripes already as the board has been very active regarding discussions and making decisions relating to the COVID-19 pandemic.

We are very fortunate to have five new medical professionals join our Medical & Scientific Advisory Board (MSAB) as well. Drs. Crystal Aguh (Johns Hopkins), Angela Christiano (Columbia University), Jeff Donovan (Donovan Hair Clinic), Loren Krueger (Emory University), and Kumar Sukhdeo (Pilaris Hair Clinic) bring their

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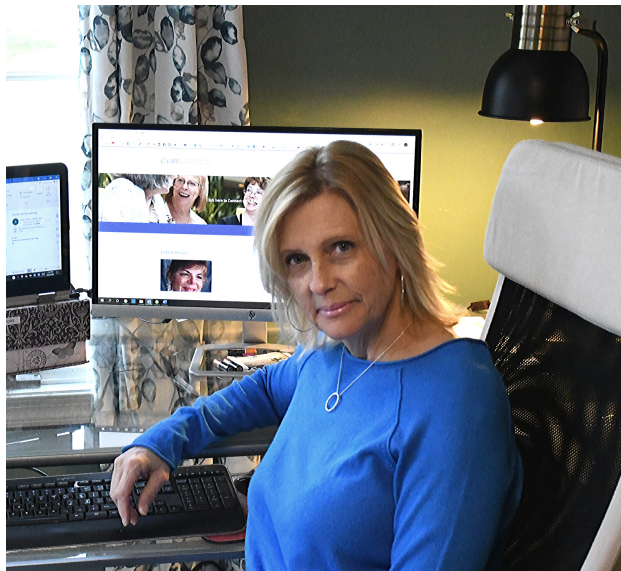
experience and passion for treating and studying scarring alopecia to CARF's very prestigious group of advisors. The MSAB serves as a vital part in guiding CARF's medical and scientific agenda, and making sure the information and services we provide are medically-sound and accurate.

Over the next few months, there is uncertainty. We are all doing our best to adjust to the changes caused by the COVID-19 pandemic. Its effect on the world, how we communicate, and how we conduct our activities, is yet to be determined. I know that when I sit down to write my Executive Director report in June, I have positive and exciting things to share! In the meantime, let's keep the faith and know that Colleen and I are working harder than ever to unite and support the scarring alopecia community.

Warmly,



Jean Pickford



2020 Board of Directors

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Christine Janus, Treasurer

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Kris Wharton

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Jerry Shapiro, MD

Kumar Sukhdeo, MD, PhD

Ken Washenik, MD

TUESDAYS WITH CARF: IN THE KNOW WEBINAR SERIES

Members asked and we listened! Mark your calendars - CARF will be hosting monthly live educational webinars about relevant topics for scarring alopecia patients. These new one-hour webinar series called *In the Know*, will feature a live lecture followed by patient Q & A with doctors and other experts.

We are kicking it off on Tuesday, April 21, the week of our original postponed conference! Join us as 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, will be our featured speaker talking about the fundamentals of scarring alopecia. These webinars will be free, thanks to CARF's hard work to secure sponsors to underwrite the costs. Each topic and speaker will be announced a few weeks prior to each webinar.

NEXT UP:

Tuesday, April 21, 2020

8:00 pm EST

Dr. Jeff Donovan

Fundamentals of Scarring Alopecia

CARF Facebook LIVE

CARF is excited to launch webinars via Facebook Live. FB live is a feature of the Facebook social network that uses the camera on a computer or mobile device to broadcast real-time video to Facebook. CARF can broadcast LIVE and house the content for future viewing. CARF members do not have to be a member of FB to view live events. CARF will also be broadcasting via YouTube for those who are more comfortable with that platform.

Mark Your Calendars

- Tuesday, May 12 – 8:00 pm EST
- Tuesday, June 8 – 8:00 pm EST
- Tuesday, July 7 – 8:00 pm EST
- Tuesday, August 11 – 8:00 pm EST
- Tuesday, September 8 – 8:00 pm EST
- Tuesday, October 6 – 8:00 pm EST
- Tuesday, November 10 – 8:00 pm EST
- Tuesday, December 8 – 8 pm EST



Click on the icons below to find CARF on the web!

