



Pros and Cons of Topical and Oral Minoxidil (Rogaine and Loniten)

By Hannah Lynch, MD Candidate Class of 2025, New York Institute of Technology College of Osteopathic Medicine

Reviewed by Maria Hordinsky, MD

Minoxidil is an oral drug that was first used for hypertension in the 1970's. At the time, clinicians noted that patients receiving oral minoxidil were also observing hair growth.⁴ Realizing this, the market pivoted. Topical minoxidil evolved, and 2% or 5% minoxidil, also known as Rogaine, is now the hair loss product we use today. It is approved by the FDA for the treatment of female and male androgenetic alopecia (AGA) and is being used off-label to treat different hair disorders where there is opportunity to grow hair.⁴

First, let us discuss the topical form of minoxidil. The brand name is Rogaine and is an over-the-counter treatment. The topical form is a liquid that can be found in either a 2% or 5% solution. The recommendation is to apply 1 mL twice daily. A 5% foam formulation is also available with instructions to apply twice a day for men with male pattern baldness and once a day for women with pattern thinning.⁶ In 2019, a 10% solution was studied but was found to be less effective for hair regrowth and more irritating than the 5% solution.¹

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**Visit Our Website
for the Newest Program**



The Journey to Acceptance Program is an evolving toolbox of resources for patients built around a single theme – *know that you won't always feel this way.*



CORRESPONDENCE CORNER

Dear CARF - Students and dermatologists from the GW School of Medicine, with the support of the Ward 8 Council, are having a skin health fair on November 13th in Ward 8 of Washington DC, one of the poorest regions in our nation's capital with a population that is 92% black and without any dermatology clinics. There are multiple conditions that often go untreated due to lack of awareness or disease misconceptions, leading to severe disease that negatively impacts quality of life. We aim to increase awareness of five of the most common skin diseases as well as skin cancer, to improve personal recognition and understanding of treatment options and risks of untreated disease and impress upon community members when appropriate to seek care. Thank you for providing attendees with informational pamphlets, brochures, or flyers on CCCA.



SUPPORT GROUPS

CONNECT. SUPPORT. THRIVE.

CARF has moved to a monthly support group model to ensure all patients have the opportunity to join as many meetings as possible.

It goes without saying that the past few years required a great deal of flexibility. CARF's ability to pivot and move to a virtual platform was met with great success and made it clear CARF members want to connect. Our new monthly meetings will allow members to share and connect more frequently than ever before!



UPCOMING SUPPORT GROUP DATES

CCCA-USA

January 16, 2022 - 7 pm EST

CCCA United Kingdom

January 11, 2022 - 7 pm BST/2 pm EST

April 12, 2022 - 7 pm BST/2 pm EST

North America - All Types

January 4, 2022 - 8 pm EST

Visit www.carfintl.org and click on support to register for upcoming meetings!



EXECUTIVE DIRECTOR INTERVIEW



Jean Pickford

Tell us how you first got involved with CARF.

It started from my relationship with Rita Wanser, CARF's long-term president. We both attended dermatologic meetings where Rita represented CARF, and I was the director of an organization representing another rare dermatologic disease called ichthyosis. At a meeting of the American Academy of Dermatology in early March 2017, Rita invited me to lunch. She shared the history of CARF and how the organization was in a transition phase looking for a nonprofit leader. I was immediately interested and threw my name into the candidate pool. Fast forward a few months later, I was honored and excited to be at the helm of this impactful organization.

What were your immediate goals when you first came onboard?

I had experience from previous roles in other organizations, and knew I had to focus my immediate attention to two areas: value and infrastructure. I needed to highlight and add to CARF's value for our members, new patients, medical professionals, and industry. Also high on my priority list were infrastructure components

like our communication and fundraising plans and increasing the use of technology for greater outreach. Every link in the chain of growth is important: more value = more patients = more attention = more funding for research and education.

What do you like most about working for CARF?

By far, it is the members, board, and staff! Every person engaged with this organization brings their own unique story as to why they are involved. Whether it is an affected member, a doctor who treats patients, a staff member who works so hard to get the job done, or a board member who donates their time to govern our important work, it is inspiring to be a part of CARF.

So far, what has been your favorite project at CARF?

Not to be cliché, but I really like everything I do for CARF. If I had to choose one favorite, it would be our virtual webinars. It was so disappointing to cancel our 2020 national conference in Nashville because of the pandemic. I know how much learning from experts and sharing with peers means to our community. But after we rallied together and changed our course to an online educational program, CARF was able to reach even more patients. It was quite remarkable! I am grateful to my staff and collaborators for their energy and expertise in making this happen. And we'll be doing more in 2022.

What do you wish people knew about CARF?

I wish people knew that scarring alopecia is a growing epidemic and affecting more people than ever before. I wish that there were more knowledgeable physicians who could recognize



FROM INSPIRED TO INSPIRING

Part one of a two part series

by Kris Wharton and Debra Lajeunesse



Debra Lajeunesse

I've always struggled with self-confidence. I don't know if it stems from always being "the new kid" growing up (we moved a lot) or something else, but deep down, I'm always uncertain and terrified of being embarrassed.

I'd always loved watching musicals and other performances, but had never danced myself. My husband and I took a few lessons, as a "date night" activity, and I noticed there were many ladies without partners taking lessons at the studio. When he got busier at work and decided not to continue with the lessons, I began individual instruction and that's really when everything changed. Just dancing in the studio and being okay with making mistakes (and I make A LOT) in front of people was really pushing me out of my comfort zone. I was watching myself in the mirror (ugh) when my instructor suggested that I start competing! I didn't even know there were ballroom dance competitions.

Fast forward two years. I've now participated in a dozen or so competitions, both regionally and



Debra Lajeunesse

nationally, and I haven't died. We all walk into our hair and makeup appointments, with naked faces and many of us with hair pieces, extensions or wigs in our bags, to be transformed in ways I never knew possible. I still tremble at the beginning of every day of competing, but I get out on the dance floor and slowly relax and trust my training and my partner. I've never won a championship, but I now make it to the finals. I'm still nervous, but I smile anyway. I've learned dancers come in all shapes and sizes. I know there will always be other dancers who will exceed my abilities, but I'm proud to see where I have grown. It has brought me immeasurable joy, and is helping me believe in myself, just as I am.



Kris Wharton

At 51, it was easy for me to think I'm too old to learn new tricks or resume a favorite pastime from years ago because life was just too busy. We put ourselves on the back burner to take care of everyone else's needs and years later find we forgot to nurture that beautiful creative gift we possess that now lies dormant. A gift that could bring much joy to ourselves and others.

Continued on next page

FROM INSPIRED TO INSPIRING

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Throughout high school and college, I performed in many theater productions and earned a bachelors' degree in technical theater with a minor in music. Sadly, after college I married a man who turned out to be an abuser of many things, including me. I lost myself during those 12 years but finally gained enough courage to get a divorce and move far away from the manipulation and control.

Since then, I met and married a wonderful man and found much satisfaction in my career, yet something was always niggling in the back of my mind: a desire to audition for a production at one of our local community theaters. I'd peruse their websites looking for the "right" production to audition for but always found an excuse not to... until I met Debra.

Debra was newly hired by CARF and she and I were getting to know each other over the phone. When I learned that she competes in ballroom dancing, I was impressed! And when I learned she had only been dancing for two years, the lightbulbs started to pop on in my head. Wow. Debra. Learning a new craft...moving past her fears...finding, as she calls it, "immeasurable joy." I want some of that. I need some of that.

In October, I learned that open auditions were just ten days away for a two-weekend run in December of *It's a Wonderful Life*. Do you watch the old Jimmy Stewart-Donna Reed classic around Christmastime? It's one of my favorites. I decided to audition.

I felt like I had come home. I'm cast in the production, playing multiple roles as the play's setting is staged as a 1940's radio play. I am having so much FUN! I didn't realize how much FUN I was missing until I started having it again!



Kris Wharton (right)

I'm making new friends, laughing a lot, polishing my characters, and looking forward to opening night and performing my heart out.

Is there a hobby or creative gift you've set aside – or one you haven't pursued – for whatever reason? Perhaps it's time to open that gift this season and discover the joy that is waiting there for you...



Scarring Alopecias Are Associated with Inflammation within the Upper Parts of the Hair Follicle

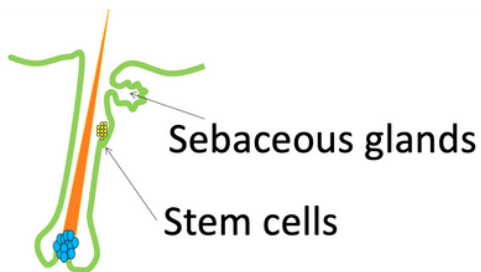
by Dr. Jeff Donovan, a Canadian and US board-certified dermatologist, specializing exclusively in hair loss, and a member of CARF's Board of Directors.



Jeff Donovan, MD

The main scarring alopecias are associated with inflammation in the upper part of the hair follicle. When you perform a biopsy of a patient with an active scarring alopecia, there's one finding that is often noted when one looks at that biopsy under the microscope: inflammation!

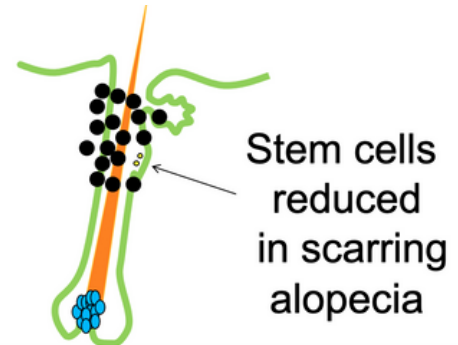
Inflammation in the primary scarring alopecias commonly occurs in a consistent location for every scarring alopecia - in the upper part of the follicle. This part of the follicle is known as the "isthmus."



The isthmus is home to some of the most precious cells of the hair follicle known as stem cells. Stem cells are cells that hide out in reserve and can produce a brand-new hair when called upon to do so during each hair cycle.

This inflammation that accumulates in the isthmus is felt to contribute to a destruction of stem cells.

Recent research also suggests that inflammation in the isthmus also encourages many stem cells



Inflammation in the primary scarring alopecias occurs in the upper parts of the hair follicle known as the isthmus. This inflammation contributes to the progressive loss of stem cells. In some scarring alopecias, this loss of stem cells appears to be due to the death of stem cells. In others scarring alopecias, death of stem cells may occur alongside a transition of stem cells to other types of cells that have no regenerative ability. This is called the epithelial mesenchymal transition or EMT.

to quit their job as stem cells and transform to other types of cells (a process called epithelial mesenchymal transition or EMT).

Scarring Alopecias are Associated with Loss of Immune Privilege

To hair researchers, the inflammation that accumulates in the isthmus indicates a loss of something called "immune privilege." Normally, the human body does absolutely everything it can to protect these precious stem cells from anything that could damage them. Normally, inflammatory cells in the blood stream and skin are not allowed access to stem cells.

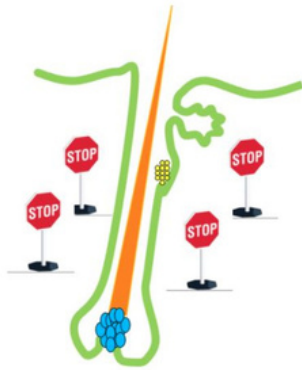
In scarring alopecias, these steps that are supposed to protect the stem cells break down. Inflammation accumulates around the isthmus and stem cells start disappearing. The ability of that follicle to make a new hair again progressively dwindles. Loss of immune privilege is a key area of hair research.

Scarring Alopecias Are Associated with Inflammation...

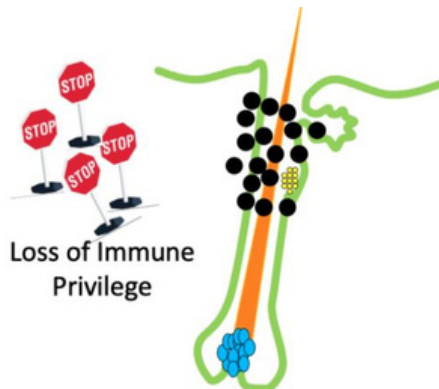
by Jeff Donovan, MD

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Immune Privilege



Loss of Immune Privilege



The Clinical Connection: What do patients experience?

A patient with scarring alopecia does not shout out that their stem cells are disappearing. They do not tell their doctors that there has been a loss of immune privilege. Patients do however report that their scalp itches, or burns, or is tender, or is red, or has more shedding than they think is normal, or they are developing areas of hair loss.

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Topical minoxidil is relatively easy to apply. You can simply massage it into the area of hair loss if you are experiencing male pattern baldness or, if there is thinning hair, it is easier to make part widths and apply directly to the scalp. If using the product twice a day, a bottle or canister should last a month. Topical minoxidil is considered safe for colored hair and one can style one's hair however you'd like after application. Within 3–6 months, the use of topical minoxidil should show results.⁶

Topical minoxidil has no risk of severe systemic side effects (e.g. weight gain)⁶, however there are other side effects that might be bothersome. The most common ones include hypertrichosis (excessive hair growth in other areas such as the face), itchy skin, and scalp scaling.⁴ These side effects are slightly more common in women, but also tend to occur more often with the 5% liquid form.⁶ Reducing frequency of application may be associated with less hypertrichosis and if scalp itching and scale persist, your doctor may recommend allergy testing, since there is the possibility of being allergic to a chemical within the product. Also, when starting topical minoxidil, hair shedding is frequently reported for the first few weeks.⁴ This can seem alarming, but it is expected and will resolve. This occurs as the hair cycle is "forced" to go into the growth phase called anagen. If you discontinue applying topical minoxidil, hair growth and side effects are expected to go away.⁶

Next, let's discuss the oral form of minoxidil. The brand name is Loniten and it must be prescribed by a physician. The typical oral minoxidil dose

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for pattern baldness ranges between 0.25–1.25 mg daily.⁴

Oral minoxidil is a more recent treatment for hair loss. A randomized clinical trial in 2019 compared 1 mg of oral minoxidil to the 5% liquid form and found them to be equally effective.³

This is exciting news, as it showed oral minoxidil to be another effective and safe option for people with hair loss conditions. For many, an advantage of the oral form is the simplicity of just taking a pill once a day. This makes treatment easier to consistently maintain.⁵ Additionally, oral minoxidil has slightly different side effects than topical minoxidil. If a patient is struggling with skin irritation due to topical minoxidil, oral minoxidil may be a better alternative.⁴

Oral minoxidil does have side effects though. The most common side effect of the oral form is hypertrichosis. It may occur in up to 27% of patients taking the 1 mg oral form versus only 4% of patients using the liquid form.³ Other less common side effects include weight gain and swelling in the legs.⁴ However, all these side effects are generally mild and well tolerated.³

Additionally, the lower the dose or oral minoxidil, the less likely and severe the side effects are. The initial hair shedding phase with topical minoxidil is also seen while using oral minoxidil, and will resolve just as quickly.

However, it must be mentioned that oral minoxidil in larger doses can cause serious systemic side effects, including increased heart rate, weight gain, and other cardiovascular symptoms. Due to this, patients with severe hypertension and/or those who are at an increased risk for heart attacks should be careful when using oral minoxidil. Medical

professionals also recommend avoiding minoxidil during pregnancy and lactation, as this has not been well researched.⁶

Here is a table summarizing some of the pros and cons between topical and oral minoxidil:

	Topical Minoxidil (Rogaine)	Oral Minoxidil (Loniten)
Pros	Over the counter Easy to apply Safe from serious side effects	Taken once a day In pill form No skin irritation
Cons	Applied twice a day Hypertrichosis (excessive hair growth) Itchy skin Scaling skin	Prescribed Hypertrichosis (excessive hair growth) Risk of serious side effects

With all of this in mind, let's recap. Minoxidil is generally effective for treating hair loss disorders and is a great option to try. Most people begin with a topical minoxidil, Rogaine, and evaluate the effectiveness after 6 or more months. If the side effects are bothersome, or it is just not working, the low-dose Loniten is the next option. However, the key to either treatment is consistency. As always, be sure to discuss with your dermatologist to determine what will be the best fit for you.

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MEET OUR MEMBERS

Courtney H. Shares her Story



Suddenly in 2017 my scalp became extremely sensitive, even to the touch. At times it felt like a migraine in the center of the scalp. Often it felt like my scalp was bruised. Other times I would feel a hot tingly pain that would shoot in the middle of my scalp. Throughout my career as a hairstylist, I've encountered alopecia clients and believed myself to be well versed on hair loss and other scalp maladies. I used my professional knowledge to self diagnose the symptoms as a result of life stressors. I was in denial that anything more significant could be the cause of my hair woes. Sadly, *once again*, I had despondency surrounding my hair.

Unfortunately, styling my hair became so painful! I began to wear scarves daily to avoid touching it and, painfully styling my hair for

"Suddenly in 2017 my scalp became extremely sensitive, even to the touch."

events where a headwrap would be deemed inappropriate.

Then in 2018 a family member's hair began to fall out. She came to me for professional advice. During her consultation, I discovered that we both had similar symptoms. We shared about the painful problem of hair loss that suddenly appeared for us both. I began doing intense research and came across some information on scarring alopecia. After two failed appointments, I found a dermatologist who confirmed with a blood test and biopsy that both my family member and I had CCCA. I became slightly depressed at the news because the idea of having scarring alopecia was a total bummer!!!

One, it's physically painful, always leaving me on edge about how, when, and what will cause my pain. Secondly, it is emotionally painful knowing that I will be bald and possibly genetically pass this to my children. But there was a silver lining -I finally had answers! This hot, painful, sore scalp had a name. In the words of SunTzu "If you know the enemy and know yourself, you need not fear the result of a hundred battles."

My hair journey started with self love, and progressed to a creative career, and now to advocacy, which led me to CARF! I am ecstatic to have a network of fellow patients and medical professionals that understand my condition. Joining this organization this year further affirms that CCCA has a greater purpose in my life and that WE are not alone!

"My hair journey started with self love..."

CARF IS RAISING RESEARCH FUNDS NEEDED TO LAUNCH THE CICATRICIAL ALOPECIA PREVALENCE STUDY!



There are published reports indicating an emerging epidemic of certain types of scarring alopecias. CARF physician experts often speak anecdotally of the increasing numbers of new patients they see with a scarring alopecia diagnosis. There is little understanding of just how many patients are affected by these disorders. While some data has been reported over the years, CARF wants to broaden our knowledge and build upon existing estimates.

The evidence-based foundation upon which to build treatment guidelines and predict outcomes remains painfully thin. There is an enormous need to improve the field's understanding of these irreversible and traumatizing alopecias, for which many key parameters remain unclear. A first step in this process is to quantify the prevalence as well as demographic and ethnic distribution within defined populations. In plain language, how many people today are affected with scarring alopecia?

CARF is taking the lead in expanding our understanding of prevalence data by raising funds to conduct a **Cicatricial Alopecia Prevalence (CAP) Study**. This effort requires three critical components and we are two-thirds of the way there:

- A plan, data, and methodology (*done*)
- Authorities to lead the study (*done*)
- Dedicated funding to support the work (*still needed*)

For the past few years, we have been asking for donations to support CARF as an organization, but this request is different.

It is literally the beginning of our research process to have robust quantifiable data to gain the attention that affected patients need and deserve. Every donation counts and will add up – so give whatever you can to help build the pieces to the scarring alopecia research puzzle.

Donate Today to Fund the CAP Study in 2022

Please join CARF today in this ground-breaking endeavor by donating to the CAP Study Fund. All donations will be applied to this research project and are fully tax-deductible to the extent allowed by law.

THE MANE NETWORK

CARF has partnered with Dr. Maryanne Senna and Massachusetts General Hospital (MGH) Hair Academic Innovative Research (HAIR) Unit to provide FREE training and education for hair salons, their personnel, and hair care students about scarring hair loss disorders.



JOIN US

CARF launched National Scarring Alopecia Awareness Month (NSAAM) to increase education and awareness of scarring hair loss. We created the Mane Network as a way to provide scarring hair loss education, training, and support to hair salons, their personnel, and hair care students.

BENEFITS

Professional Development
Continuing Education
CARF Seal of Recognition

Private Networking Group
Building Workplace Culture
Quarterly e-blasts

The Mane Network Membership is FREE to hair salons, their personnel, and hair care students. Contact CARF at info@carfintl.org with any questions.

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EXECUTIVE DIRECTOR INTERVIEW

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the signs for prompt treatment. But most of all, I wish more people knew about CARF - the only patient organization in the world that is solely dedicated to this special hair loss condition.

What do you do when you are not working for CARF?

I also work for two other rare disease organizations in addition to CARF, which is very fulfilling. I am a mom to three children, ages 23, 21 and 15, and stay active with frequent trips to the beach with my husband, Steve, of 28 years. I also enjoy cycling, yoga, and my newest obsession - pickleball.

Is there anything else you would like to share?

Yes! I want our members and community to know that CARF is working on some major projects and plans will be announced in a few weeks. We will be publicizing our new four-year strategic plan with five major goals and fifteen key objectives for the scarring alopecia community.