

What you should know about
**CICATRICAL
ALOPECIA**



C.A.R.F.

CICATRICAL ALOPECIA RESEARCH FOUNDATION

www.carfintl.org

The Cicatricial Alopecia Research Foundation (CARF) is the world center for those with cicatricial alopecia.

The Foundation

- provides funds for research to find effective treatments and a cure
- supports education and advocacy
- raises public awareness

The C.A.R.F. is a tax exempt, not-for-profit organization under Section 501(c)(3) of the Internal Revenue Code.

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FREQUENTLY ASKED QUESTIONS ABOUT CICATRICIAL (SCARRING) ALOPECIA

What is cicatricial alopecia or scarring alopecia?

The term “cicatricial alopecia” refers to a diverse group of rare disorders that destroy the hair follicle, replace it with scar tissue, and cause permanent hair loss. In some cases, hair loss is gradual, without symptoms, and is unnoticed for long periods. In other cases, hair loss is associated with severe itching, burning and pain and is rapidly progressive. The inflammation that destroys the follicle is below the skin surface and there is usually no “scar” seen on the scalp. Affected areas of the scalp may show little signs of inflammation, or have redness, scaling, increased or decreased pigmentation, pustules, or draining sinuses. Cicatricial alopecia occurs in otherwise healthy men and women of all ages and is seen worldwide.

Are there different kinds of cicatricial alopecia?

Yes, cicatricial alopecias are classified as primary or secondary. This discussion is confined to the primary cicatricial alopecias in which the hair follicle is the target of the destructive inflammatory process. In secondary cicatricial alopecias, destruction of the hair follicle is incidental to a non-follicle-directed process or external injury, such as severe infections, burns, radiation, or tumors.

Primary cicatricial alopecias are further classified by the type of inflammatory cells that destroy the hair follicle during the active stage of the disease. The inflammation may predominantly involve lymphocytes or neutrophils. Cicatricial alopecias that involve predominantly lymphocytic inflammation include lichen planopilaris, frontal fibrosing alopecia, chronic cutaneous lupus erythematosus, central centrifugal alopecia, pseudopelade (Brocq), alopecia mucinosa, and keratosis follicularis spinulosa decalvans. Cicatricial alopecias that involve predominantly neutrophilic inflammation include folliculitis decalvans, tufted folliculitis, and dissecting cellulitis. Sometimes the inflammation shifts from a predominantly neutrophilic process to a lymphocytic process. Cicatricial alopecias with a mixed inflammatory infiltrate include folliculitis keloidalis and erosive pustular dermatosis.

What causes cicatricial alopecia?

The cause of the various cicatricial alopecias is poorly understood. However, all cicatricial alopecias involve inflammation directed at the hair follicle, usually the upper part of the follicle where the stem cells and sebaceous gland (oil gland) are located. If the stem cells and the sebaceous gland are destroyed, there is then no possibility for regeneration of the hair follicle and permanent hair loss results.

Cicatricial alopecias are not contagious.

Who is affected by cicatricial alopecias?

Cicatricial alopecias affect both men and women, most commonly young adults although all ages may be affected. Keratosis follicularis spinulosa decalvans usually manifests itself in the teenage years. Epidemiologic studies have not been performed to determine the incidence of cicatricial alopecias. In general, they are not common.

There have been a few reports of cicatricial alopecia occurring in a family. However, the majority of patients with cicatricial alopecia have no family history of a similar condition. Central centrifugal alopecia may affect black women most commonly. Frontal fibrosing alopecia is seen most commonly in post-menopausal women. While it is possible to have more than one type of hair loss condition, non-scarring forms of hair loss do not turn into scarring forms of hair loss.

Are cicatricial alopecias associated with other illnesses?

In general, cicatricial alopecias are not associated with other illnesses. Patients with chronic cutaneous lupus erythematosus may have an increased personal and family history of autoimmune disorders.

How are cicatricial alopecias diagnosed?

A scalp biopsy is essential for the diagnosis of cicatricial alopecia and is the necessary first step. Findings of the scalp biopsy, including the type of inflammation present, location and amount of inflammation, and other changes in the scalp, are necessary to diagnose the type of cicatricial alopecia, to determine the degree of activity, and to select appropriate therapy.

Clinical evaluation of the scalp is also important. Symptoms of itching, burning, pain or tenderness usually signal ongoing activity. Signs of scalp inflammation include redness, scaling, and pustules. However, in some cases there are few symptoms or signs and only the scalp biopsy demonstrates the active inflammation. The overall extent and pattern of hair loss is noted and sometimes photographed for future comparison. A hair "pull test" is performed to identify areas of active disease in which follicles are easily pulled out. The pulled hairs are mounted on a slide and the hair bulbs are viewed with a microscope to determine how many are growing hairs and how many are resting hairs. In addition, if pustules are present, cultures may be performed to identify which microbes, if any, may be contributing to the inflammation. A thorough evaluation that includes all of these parameters is important in diagnosing a cicatricial alopecia and in identifying features in individual patients that will help the selection of therapy.

Diagnosis and treatment of cicatricial alopecias is often challenging. For this reason, it is helpful to be evaluated by a dermatologist with a special interest or expertise in scalp and hair disorders, and who is familiar with current diagnostic methods and therapies. A hair specialist who is experienced in the evaluation and treatment of patients with cicatricial alopecias may be found by contacting the American Academy of Dermatology (www.aad.org) or the North American Hair Research Society (www.nahrs.org).

How are cicatricial alopecias treated?

As mentioned above, primary cicatricial alopecias are classified by the predominant type of inflammatory cells that attack the hair follicles: i.e., lymphocytes, neutrophils, or mixed inflammatory cells. Treatment strategies are different for each subtype and detailed treatment options are beyond the scope of this discussion. However, certain general principals are reviewed below.

Treatment of the lymphocytic group of cicatricial alopecias (including lichen planopilaris, frontal fibrosing alopecia, chronic cutaneous lupus erythematosus, central centrifugal alopecia, pseudopelade (Brocq), alopecia mucinosa, and keratosis follicularis spinulosa decalvans) involves use of anti-inflammatory medications. The goal of treatment is to decrease or eliminate the lymphocytic inflammatory cells that are attacking and destroying the

hair follicle. Oral medications may include hydroxychloroquine, doxycycline, mycophenolate mofetil, cyclosporine, or corticosteroids. Topical medications may include corticosteroids, topical tacrolimus, topical pimecrolimus, Derma-Smoothe/FS scalp oil; Triamcinolone acetonide (a corticosteroid) may be injected into inflamed, symptomatic areas of the scalp.

Treatment of the neutrophilic group of cicatricial alopecias (folliculitis decalvans, tufted folliculitis, and dissecting cellulitis) is directed at eliminating the predominant microbes that are invariably involved in the inflammatory process. Oral antibiotics are the mainstay of therapy, and topical antibiotics may be used to supplement the oral antibiotics. Isotretinoin is sometimes helpful in controlling the neutrophilic group, especially dissecting cellulitis.

Treatment of the mixed group of cicatricial alopecias (folliculitis keloidalis and erosive pustular dermatosis) may include antimicrobials, isotretinoin (especially for folliculitis keloidalis), and anti-inflammatory medications.

You should discuss any treatment with your dermatologist who will also explain potential side effects, as well as laboratory tests that are needed before starting treatment and sometimes are monitored during treatment.

The course of cicatricial alopecia is usually prolonged. Treatment is continued until the symptoms and signs of scalp inflammation are controlled, and progression of the condition has been halted. In other words, itching, burning, pain and tenderness have

cleared, scalp redness, scaling, and/or pustules are no longer present, and the hair loss has not extended. Treatment may then be stopped. Unfortunately, the cicatricial alopecias often re-activate after a quiet period of one or more years, and treatment must be started again.

Because of the above last statement, surgical treatment is not an option in most cases except under certain conditions: if the disease has been inactive for many years and the area of hair loss is small, then surgical removal of the scarred scalp and/or hair transplants may be considered for cosmetic benefit. Folliculitis keloidalis is one exception in that excision of the affected scalp at the back of the head (scalp reduction) may provide relief for the patient.

Will my hair grow back?

Hair will not regrow once the follicle is destroyed. However, it may be possible to treat the inflammation in and around surrounding follicles before they are destroyed and for this reason it is important to begin treatment as early as possible to halt the inflammatory process. Minoxidil solution (2% or 5%) applied twice daily to the scalp may be helpful to stimulate any small, remaining, unscarred follicles. The progression of hair loss is unpredictable. In some cases, progression is slow and there is always sufficient hair remaining to cover the affected scalp areas; in other cases, progression can be rapid and extensive.

What signs and symptoms should I watch for?

It is important to continue to watch for symptoms and signs of active disease during and after treatment to ensure that the disease is responding adequately and has not re-activated after therapy has been discontinued. Response to therapy may be indicated by the resolution of scalp symptoms such as itching, burning, pain or tenderness, by improvement in the signs of scalp inflammation such as decreased redness, scaling or pustules, and by halting the progression of hair loss. A dermatologist can follow your cicatricial alopecia using these guidelines, and with the pull test. Photographs of the scalp may be useful in monitoring the progression and halting of progression of the disease.

How should I care for my hair?

Hair care products and shampoos can generally be used with any frequency desired, as long as the products are non-irritating to the scalp. Dermatologists may recommend specific shampoos and products to decrease scalp symptoms, scaling and inflammation. Hair pieces, wigs, hats, scarves may be used freely.

Does CARF have a website?

Yes, the website is: www.carfintl.org and is updated on a regular basis to include newsworthy items, information about the annual patient conference and resources.

C.A.R.F. does not endorse any of the medications, treatments, or products. Please consult with your physician before considering any of the drugs or treatments.

YES, I want to help myself and others with cicatricial alopecia. Enclosed is my donation to help the Cicatricial Alopecia Research Foundation with its programs of support, research, and education.

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