

*Questions
& Answers
about . . .*

**Alopecia
Areata**

*National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
National Institutes of Health
Public Health Service • U.S. Department of Health and Human Services*

For Your Information

This publication contains information about medications used to treat the health condition discussed in this booklet. When this booklet was printed, we included the most up-to-date (accurate) information available. Occasionally, new information on medication is released.

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This booklet contains general information about alopecia areata (al-oh-PEE-shah ar-ee-AH-tah). It describes what alopecia is, its causes, and treatment options. Information is also provided on current research. If you have further questions after reading this booklet, you may wish to discuss them with your doctor.

What Is Alopecia Areata?

Alopecia areata is considered an autoimmune disease, in which the immune system, which is designed to protect the body from foreign invaders such as viruses and bacteria, mistakenly attacks the hair follicles, the tiny cup-shaped structures from which hairs grow. This can lead to hair loss on the scalp and elsewhere.

In most cases, hair falls out in small, round patches about the size of a quarter. In many cases, the disease does not extend beyond a few bare patches. In some people, hair loss is more extensive. Although uncommon, the disease can progress to cause total loss of hair on the head (referred to as alopecia areata totalis) or complete loss of hair on the head, face, and body (alopecia areata universalis).

What Causes It?

In alopecia areata, immune system cells called white blood cells attack the rapidly growing cells in the hair follicles that make the hair. The affected hair follicles become small and

drastically slow down hair production. Fortunately, the stem cells that continually supply the follicle with new cells do not seem to be targeted. So the follicle always has the potential to regrow hair.

Scientists do not know exactly why the hair follicles undergo these changes, but they suspect that a combination of genes may predispose some people to the disease. In those who are genetically predisposed, some type of trigger—perhaps a virus or something in the person’s environment—brings on the attack against the hair follicles.

Who Is Most Likely To Get It?

Alopecia areata affects an estimated four million Americans of both sexes and of all ages and ethnic backgrounds. It often begins in childhood.

If you have a close family member with the disease, your risk of developing it is slightly increased. If your family member lost his or her first patch of hair before age 30, the risk to other family members is greater. Overall, one in five people with the disease have a family member who has it as well.

Is My Hair Loss a Symptom of a Serious Disease?

Alopecia areata is not a life-threatening disease. It does not cause any physical pain, and people with the condition are generally healthy otherwise. But for most people, a disease

that unpredictably affects their appearance the way alopecia areata does is a serious matter.

The effects of alopecia areata are primarily socially and emotionally disturbing. In alopecia universalis, however, loss of eyelashes and eyebrows and hair in the nose and ears can make the person more vulnerable to dust, germs, and foreign particles entering the eyes, nose, and ears.

Alopecia areata often occurs in people whose family members have other autoimmune diseases, such as diabetes, rheumatoid arthritis, thyroid disease, systemic lupus erythematosus, pernicious anemia, or Addison's disease. People who have alopecia areata do not usually have other autoimmune diseases, but they do have a higher occurrence of thyroid disease, atopic eczema, nasal allergies, and asthma.

Can I Pass It on to My Children?

It is possible, but not likely, for alopecia areata to be inherited. Most children with alopecia areata do not have a parent with the disease, and the vast majority of parents with alopecia areata do not pass it along to their children.

Alopecia areata is not like some genetic diseases in which a child has a 50-50 chance of developing the disease if one parent has it. Scientists believe that there may be a number of genes that predispose certain people to the disease. It is highly unlikely that a child would inherit all of the genes needed to predispose him or her to the disease.

Even with the right (or wrong) combination of genes, alopecia areata is not a certainty. In identical twins, who share all of the same genes, the concordance rate is only 55 percent. In other words, if one twin has the disease, there is only a 55 percent chance that the other twin will have it as well. This shows that other factors besides genetics are required to trigger the disease.

To learn more about the genes and other factors involved in alopecia areata risk, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is funding an alopecia areata registry. The registry is an organized network of five centers throughout the United States that will identify and register patients with the disease and collect data and blood samples (which contain genes). Data, including genetic information, will be made available to researchers studying the genetic basis and other aspects of disease and disease risk. (For more information about the registry, see “How Can I Take Part In Research?” on page 16.)

Will My Hair Ever Grow Back?

There is every chance that your hair will regrow, but it may also fall out again. No one can predict when it might regrow or fall out. The course of the disease varies from person to person. Some people lose just a few patches of hair, then the hair regrows, and the condition never recurs. Other people continue to lose and regrow hair for many years. A few lose all the hair on their head; some lose all the hair on

their head, face, and body. Even in those who lose all their hair, the possibility for full regrowth remains.

In some, the initial hair regrowth is white, with a gradual return of the original hair color. In most, the regrown hair is ultimately the same color and texture as the original hair.

What Can I Expect Next?

The course of alopecia areata is highly unpredictable, and the uncertainty of what will happen next is probably the most difficult and frustrating aspect of the disease. You may continue to lose hair, or your hair loss may stop. The hair you have lost may or may not grow back, and you may or may not continue to develop new bare patches.

How Is It Treated?

While there is neither a cure for alopecia areata nor drugs approved for its treatment, some people find that medications approved for other purposes can help hair grow back, at least temporarily. The following are some treatments for alopecia areata. Keep in mind that while these treatments may promote hair growth, none of them prevent new patches or actually cure the underlying disease. Consult your health care professional about the best option for you.

- **Corticosteroids**—Corticosteroids are powerful anti-inflammatory drugs similar to a hormone called

cortisol produced in the body. Because these drugs suppress the immune system if given orally, they are often used in the treatment of various autoimmune diseases, including alopecia areata. Corticosteroids may be administered in three ways for alopecia areata:

- **Local injections**—Injections of steroids directly into hairless patches on the scalp and sometimes the brow and beard areas are effective in increasing hair growth in most people. It usually takes about 4 weeks for new hair growth to become visible. Injections deliver small amounts of cortisone to affected areas, avoiding the more serious side effects encountered with long-term oral use. The main side effects of injections are transient pain, mild swelling, and sometimes changes in pigmentation, as well as small indentations in the skin that go away when injections are stopped. Because injections can be painful, they may not be the preferred treatment for children. After 1 or 2 months, new hair growth usually becomes visible, and the injections usually have to be repeated monthly. The cortisone removes the confused immune cells and allows the hair to grow. Large areas cannot be treated, however, because the discomfort and the amount of medicine become too great and can result in side effects similar to those of the oral regimen.

- **Oral corticosteroids**—Corticosteroids taken by mouth are a mainstay of treatment for many autoimmune diseases and may be used in more extensive alopecia areata. But because of the risk of side effects of oral corticosteroids, such as hypertension and cataracts, they are used only occasionally for alopecia areata and for shorter periods of time.
- **Topical ointments**—Ointments or creams containing steroids rubbed directly onto the affected area are less traumatic than injections and, therefore, are sometimes preferred for children. However, corticosteroid ointments and creams alone are less effective than injections; they work best when combined with other topical treatments, such as minoxidil or anthralin.
- **Minoxidil (5%) (Rogaine*)**—Topical minoxidil solution promotes hair growth in several conditions in which the hair follicle is small and not growing to its full potential. Minoxidil is FDA-approved for treating male and female pattern hair loss. It may also be useful in promoting hair growth in alopecia areata. The solution, applied twice daily, has been shown to promote hair growth in both adults and children, and may be used on the scalp, brow, and

* Brand names included in this booklet are provided as examples only, and their inclusion does not mean that these products are endorsed by the National Institutes of Health or any other Government agency. Also, if a particular brand name is not mentioned, this does not mean or imply that the product is unsatisfactory.

beard areas. With regular and proper use of the solution, new hair growth appears in about 12 weeks.

- **Anthralin** (Psoriatec)—Anthralin, a synthetic tar-like substance that alters immune function in the affected skin, is an approved treatment for psoriasis. Anthralin is also commonly used to treat alopecia areata. Anthralin is applied for 20 to 60 minutes (“short contact therapy”) to avoid skin irritation, which is not needed for the drug to work. When it works, new hair growth is usually evident in 8 to 12 weeks. Anthralin is often used in combination with other treatments, such as corticosteroid injections or minoxidil, for improved results.
- **Sulfasalazine**—A sulfa drug, sulfasalazine has been used as a treatment for different autoimmune disorders, including psoriasis. It acts on the immune system and has been used to some effect in patients with severe alopecia areata.
- **Topical sensitizers**—Topical sensitizers are medications that, when applied to the scalp, provoke an allergic reaction that leads to itching, scaling, and eventually hair growth. If the medication works, new hair growth is usually established in 3 to 12 months. Two topical sensitizers are used in alopecia areata: squaric acid dibutyl ester (SADBE) and diphenylcyclopropenone (DPCP). Their safety and consistency of formula are currently under review.

- **Oral cyclosporine**—Originally developed to keep people’s immune systems from rejecting transplanted organs, oral cyclosporine is sometimes used to suppress the immune system response in psoriasis and other immune-mediated skin conditions. But suppressing the immune system can also cause problems, including an increased risk of serious infection and possibly skin cancer. Although oral cyclosporine may regrow hair in alopecia areata, it does not turn the disease off. Most doctors feel the dangers of the drug outweigh its benefits for alopecia areata.
- **Photochemotherapy**—In photochemotherapy, a treatment used most commonly for psoriasis, a person is given a light-sensitive drug called a psoralen either orally or topically and then exposed to an ultraviolet light source. This combined treatment is called PUVA. In clinical trials, approximately 55 percent of people achieve cosmetically acceptable hair growth using photochemotherapy. However, the relapse rate is high, and patients must go to a treatment center where the equipment is available at least two to three times per week. Furthermore, the treatment carries the risk of developing skin cancer.
- **Alternative therapies**—When drug treatments fail to bring sufficient hair regrowth, some people turn to alternative therapies. Alternatives purported to help alopecia areata include acupuncture, aroma therapy, evening primrose oil, zinc and vitamin supplements,

and Chinese herbs. Because many alternative therapies are not backed by clinical trials, they may or may not be effective for regrowing hair. In fact, some may actually make hair loss worse. Furthermore, just because these therapies are natural does not mean that they are safe. As with any therapy, it is best to discuss these treatments with your doctor before you try them.

In addition to treatments to help hair grow, there are measures that can be taken to minimize the physical dangers or discomforts of lost hair.

- Sunscreens are important for the scalp, face, and all exposed areas.
- Eyeglasses (or sunglasses) protect the eyes from excessive sun, and from dust and debris, when eyebrows or eyelashes are missing.
- Wigs, caps, or scarves protect the scalp from the sun and keep the head warm.
- Antibiotic ointment applied inside the nostrils helps to protect against organisms invading the nose when nostril hair is missing.

How Will Alopecia Areata Affect My Life?

This is a common question, particularly for children, teens, and young adults who are beginning to form lifelong goals

and who may live with the effects of alopecia areata for many years. The comforting news is that alopecia areata is not a painful disease and does not make people feel sick physically. It is not contagious, and people who have the disease are generally healthy otherwise. It does not reduce life expectancy and it should not interfere with the ability to achieve such life goals as going to school, working, marrying, raising a family, playing sports, and exercising.

The emotional aspects of living with hair loss, however, can be challenging. Many people cope by learning as much as they can about the disease; speaking with others who are facing the same problem; and, if necessary, seeking counseling to help build a positive self-image. To address quality-of-life issues for alopecia areata and all other skin diseases, the NIAMS sponsored a scientific meeting in September 2002 on the burden of skin diseases.

How Can I Cope With the Effects of This Disease?

Living with hair loss can be hard, especially in a culture that views hair as a sign of youth and good health. Even so, most people with alopecia areata are well-adjusted, contented people living full lives.

The key to coping is valuing yourself for who you are, not for how much hair you have or don't have. Many people learning to cope with alopecia areata find it helpful to talk with other people who are dealing with the same problems. More than four million people nationwide have this disease

at some point in their lives, so you are not alone. If you would like to be in touch with others with the disease, the National Alopecia Areata Foundation (NAAF) can help through its pen pal program, message boards, annual conference, and support groups that meet in various locations nationwide. To find contact information for NAAF and other organizations that can help people with alopecia areata, see “Where Can I Learn More About Alopecia Areata?” on page 17.

Another way to cope with the disease is to minimize its effects on your appearance. If you have total hair loss, a wig or hairpiece can look natural and stylish. For small patches of hair loss, a hair-colored powder, cream, or crayon applied to the scalp can make hair loss less obvious by eliminating the contrast between the hair and the scalp. Skillfully applied eyebrow pencil can mask missing eyebrows.

Children with alopecia areata may prefer to wear bandanas or caps. There are many styles available to suit a child’s interest and mood—some even have ponytails attached.

For women, attractive scarves can hide patchy hair loss; jewelry and clothing can distract attention from patchy hair; and proper makeup can camouflage the effects of lost facial hair. If you would like to learn more about camouflaging the cosmetic aspects of alopecia areata, ask your doctor or members of your local support group to recommend a cosmetologist who specializes in working with people whose appearance is affected by medical conditions.

Is Research Close to Finding Better Treatments or a Cure?

While a cure is not imminent, researchers are making headway toward a better understanding of the disease. This increased understanding will likely lead the way to better treatments for alopecia areata and eventually a way to prevent or even cure it.

Alopecia research ranges from the most basic studies of the mechanisms of hair growth and hair loss in mice to testing medications and ways to apply medications to help regrow hair in people. Both the National Institutes of Health and the National Alopecia Areata Foundation support research into the disease and its treatment. Here are some areas of research that hold promise.

- **Developing an animal model**—This is a critical first step toward understanding the disease, and much progress has been made. By developing a mouse with a disease similar to human alopecia areata, researchers hope to learn more about the mechanism of the disease and eventually develop immune system treatments for the disease in people.
- **Mapping genes**—Scientists are studying the possible genetic causes and mechanism of the disease both in families that have one or more persons with the disease and in the general population. An understanding of the genetics of the disorder will aid in disease

prevention, early intervention, and development of specific therapies.

- **Studying hair follicle development**—By studying how hair follicles form in mouse embryos, researchers hope to gain a better understanding of hair cycle biology that may lead to treatments for the underlying disease process.
- **Targeting the immune system**—Several new agents found to be effective in treating psoriasis may prove to be effective in alopecia areata. These drugs work by blocking certain chemical messengers that play a role in the immune response, or by interfering with the activity of white blood cells (called T-cells) that are involved in the immune system's attack on hair follicles. New therapies for treating other autoimmune diseases like rheumatoid arthritis and lupus may also benefit patients with alopecia areata.
- **Finding better ways to administer drugs**—One limitation of current topical therapies is getting the drug to the source of the problem. Scientists are looking for a substance that penetrates the fat under the skin to deliver medication directly to hair follicles. In laboratory animals, topically applied synthetic sacs called liposomes seem to fill the bill. Studies are still needed to show whether liposomes do the same for people.

- **Understanding cytokines**—Chemical messengers called cytokines play a role in regulating the body’s immune response, whether it is the normal response to a foreign invader such a virus or an abnormal response to a part of the body. Researchers believe that by giving certain inflammation-suppressing cytokines, they may be able to slow down or stop the body’s abnormal response to the hair follicles. Because giving the cytokines systemically may cause adverse effects, they believe a topical medication using liposomes to get the agents to the root of the hair inside the follicle may be preferable.
- **Understanding stem cell biology**—Epithelial stem cells are immature cells that are responsible for regenerating and maintaining a variety of tissues, including the skin and the hair follicles. Stem cells in the follicle appear to be spared from injury in alopecia areata, which may explain why the potential for regrowth is always there in people with the disease. By studying the biology of these cells, and their immediate offspring, which seem to be targeted by the immune system, scientists hope to gain a better understanding of factors that trigger the disease.

How Can I Take Part in Research?

A good place to start is the National Alopecia Areata Registry sponsored by the NIAMS.

The registry, a network of five centers, will identify and register patients with the disease and collect information and blood samples (containing genes). Data, including genetic information, will be made available to researchers studying the genetic basis and other aspects of the disease and disease risk.

The registry is seeking U.S. residents with alopecia areata, alopecia totalis, or alopecia universalis diagnosed by a dermatologist. Although the registry itself will not be involved in any kind of treatment for alopecia areata, people who register will be made aware of studies for which they may qualify.

To take part in the registry, people don't have to live near or travel to one of the five centers; however, they do have to meet some requirements to participate. For more information, log onto the registry Web site at www.AlopeciaAreataRegistry.org or have your doctor contact:

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Where Can I Learn More About Alopecia Areata?

You can get additional information through the following organizations:

- **National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**
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E-mail: info@naaf.org
www.naaf.org

- **American Hair Loss Council**
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Fax: 412-765-3669
www.ahlc.org

Glossary

Acupuncture—a traditional Chinese system of healing in which symptoms are relieved by inserting needles beneath the skin at selected points and then stimulating the points by rotating the needles or exposing them to heat or electrical current.

Addison's disease—a condition that occurs when the adrenal glands (a pair of glands situated on top of the kidneys) fail to secrete enough corticosteroid hormones. Without treatment, the disease can be fatal.

Alopecia areata—an autoimmune, often reversible disease in which loss of hair occurs in sharply defined areas usually involving the scalp or beard, but at times every hair on the body.

Alopecia areata totalis—a form of alopecia areata characterized by the total loss of hair from the scalp and face.

Alopecia areata universalis—a form of alopecia areata in which all hair on the scalp, face, and body is lost.

Aroma therapy—the therapeutic use of essential oils (highly concentrated aromatic extracts distilled from a variety of aromatic plant materials including grasses, leaves, flowers, needles and twigs, fruit peels, wood, and roots) to promote the health of body, mind, and spirit.

Autoimmune disease—a disease that results when the immune system mistakenly attacks the body’s own tissues. Rheumatoid arthritis and systemic lupus erythematosus are autoimmune diseases (“auto” means self).

Chemotherapy—the use of strong drugs to suppress the immune system. Though originally associated with cancer treatment, chemotherapy is used for many different diseases involving the immune system.

Corticosteroids—potent anti-inflammatory hormones that are made naturally in the body or synthetically (man-made) for use as drugs. They are also called glucocorticoids. The most commonly prescribed drug of this type is prednisone.

Cyclosporine—a strong drug that suppresses the immune system. Originally developed to keep the body’s immune system from rejecting transplanted organs, cyclosporine is being used increasingly in autoimmune diseases, including (in rare cases) alopecia areata.

Diabetes—a disease in which the body does not produce or properly use insulin, a hormone that is necessary to convert sugar, starches, and other food into energy.

Evening primrose oil—the oil of a weedy plant containing the essential fatty acid gamma linolenic acid (GLA), which is converted into anti-inflammatory agents by the body. Evening primrose oil is available as a nutritional supplement and touted as a pain and inflammation reliever.

Hair bulb—a bulbous collection of actively growing cells at the base of the follicle that constantly produces a strand of hair.

Hair follicle—a small cup-shaped structure in the skin from which hair grows. The cup is lined with cells and connective tissue.

Immune system—a complex network of specialized cells and organs that work together to defend the body against attacks by “foreign” invaders such as bacteria and viruses. In some rheumatic conditions, it appears that the immune system does not function properly and may even work against the body.

Liposome—a synthetic microscopic globule made of fatty layers encapsulating drugs or other substances. Liposomes are often used to deliver substances to the body’s cells and tissues.

Pernicious anemia—a potentially dangerous form of anemia, usually caused by an autoimmune process, which results in a deficiency of vitamin B-12.

Rheumatoid arthritis—an autoimmune disease that targets primarily the membrane lining the joints, leading to pain, stiffness, swelling, and joint deformity.

Systemic lupus erythematosus—a chronic autoimmune disease of the connective tissue that can attack and damage the skin, joints, blood vessels, and internal organs.

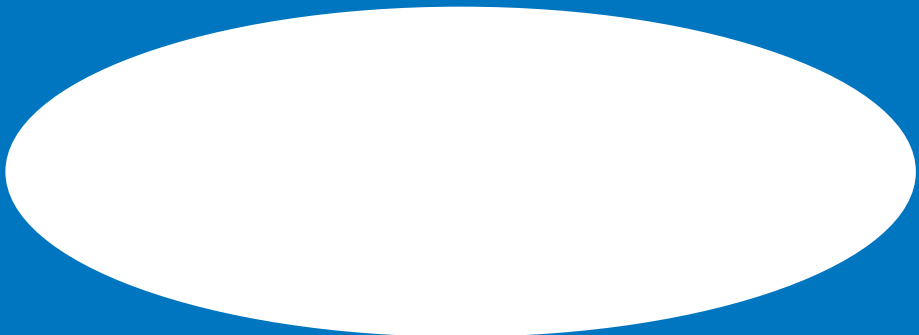
Topical sensitizers—medications that, when applied to the scalp, provoke an allergic reaction that leads to itching, scaling, and often hair growth. They include squaric acid dibutyl ester and diphenylcyclopropenone.

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