

WHAT IS ALOPECIA AREATA?



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Alopecia areata is a common autoimmune skin disease. The word alopecia means bald, while areata means patchy. Autoimmune means that your immune system mistakenly attacks the healthy tissues in your body. Alopecia areata, which often starts in childhood, causes hair loss on the scalp, face, and other body areas, like under the arms and on the legs. How much hair is lost varies. Some people lose only patches of hair, while others experience more significant hair loss.

Alopecia areata affects nearly 7 million people in the U.S. alone. About 160 million people around the world of all ages, genders, and racial and ethnic groups have the disease. About 2% of the world's population will experience alopecia areata during their lifetime.



WHAT CAUSES ALOPECIA AREATA?

Researchers don't completely understand alopecia areata – how it starts, why it affects certain people, and why some people experience more hair loss than others. It is a polygenic disease, meaning it is related to multiple genetic factors. But not everyone with the genes develops the disease. About 20% of people with alopecia areata have at least one family member who has it too. Although scientists know alopecia areata is an autoimmune disease, it's not clear what triggers the hair loss.

WHAT DOES ALOPECIA AREATA LOOK LIKE?

There are a few presentations or patterns of hair loss. The most common one is alopecia areata patchy. It causes one or more coin-sized hairless patches on the scalp and other areas. The next two are alopecia totalis (alopecia areata with complete loss of scalp hair) and alopecia universalis (loss of body hair everywhere, including the eyebrows and eyelashes, and nasal hair).

For some people, the hair grows back on its own in a few months. Others have cycles of hair loss and regrowth, but it is very unpredictable. Doctors can't tell who will have spontaneous hair regrowth and who won't.

Hair isn't the only thing affected by alopecia areata. Some people develop tiny dents, called stippling, in their nails. This is why you should remove any artificial nails or polish when you see a dermatologist. They need to evaluate the condition of your nails.

Until I connected to our huge community through NAAF, having alopecia areata was a very isolating, lonely world for me.

–Ann Hollins





HOW WILL ALOPECIA AREATA AFFECT MY LIFE?

IS THERE A CURE?

There is no cure yet for alopecia areata, but there are promising treatments. Until recently, dermatologists have been limited to therapies that may provide some hair regrowth, but their success is not consistent among patients. Most treatments for alopecia areata are used on an off-label basis. Using a drug off-label means that while the drug was not approved by the Food and Drug Administration (FDA) to treat alopecia areata, doctors learned that the drugs did help. In 2022 and 2023, two Janus kinase (JAK) inhibitors, drugs that calm down the immune system, were approved by the FDA to treat severe disease. Other medications are currently in clinical trials.

ARE RESEARCHERS WORKING ON A CURE FOR ALOPECIA AREATA?

Researchers around the world are running clinical trials to find ways to effectively treat alopecia areata. NAAF contributes to this research effort by raising private funds and awarding millions of dollars in grants to fund research at university centers throughout the world. NAAF also advocates for increased federal funding for alopecia areata research to accelerate treatment development.

How alopecia areata affects your life depends on several things. First, the disease does not generally affect your physical health, but it can affect your emotional or mental health, especially if there is extensive hair loss.

Some people don't go for treatment, preferring to use remaining hair, hats, scarves, or hair pieces to camouflage the patchy spots. Others prefer to just present themselves as they are. You need to decide what the best approach is for you or your child, if you're the parent of someone with the disease.

If you are getting depressed, anxious, or isolating yourself because of your appearance, you can find support. Speaking with a therapist or social worker may help, as may joining online or in-person support groups. You can also get support through NAAF.

WHERE CAN I GET SUPPORT?

NAAF sponsors volunteer support groups nationwide and internationally, as well as telephone support contacts. These volunteers and groups offer people with alopecia areata a chance to share feelings, experiences, and solutions to coping with the disease. Each group has a leader who has alopecia areata or is closely associated with someone who does. Support groups further NAAF's mission of researching to find a cure or acceptable treatments for alopecia areata, supporting those with the disease, and educating the public about alopecia areata.

NAAF maintains a website (www.naaf.org) with up-to-date information about alopecia areata, including information for parents and children, their teachers, and others. You will also find information about visiting a dermatologist, diagnosis, and treatment.

CONNECT WITH NAAF

NAAF is the voice of the alopecia areata community, serving the nearly 7 million Americans affected by this autoimmune disease, which causes unpredictable, often sudden and severe hair loss. Frequently dismissed as a cosmetic condition, alopecia can be a deeply traumatic experience, resulting in emotional and economic pain and social isolation. It is not just hair.

A catalyst for driving research, support, and awareness, NAAF empowers the community with more choices to embrace or live free of alopecia areata. We connect the patient, medical and scientific communities to drive research and treatment development, raise awareness to reduce stigma, and provide support to improve lives.

Founded more than 40 years ago by volunteers, NAAF serves as the voice of the alopecia areata community. Join us today and help amplify our voice!

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