Alopecia areata is a protean autoimmune skin disease resulting in the loss of hair on the scalp and elsewhere on the body. It usually starts with one or more small, round, smooth patches on the scalp and progresses to total scalp (alopecia totalis) or complete body hair loss (alopecia universalis). The scalp is the most commonly affected area, but the beard or any hair-bearing site can be affected alone or together with the scalp. Alopecia areata occurs in males and females of all ages, but onset often occurs in childhood. Over 6.5 million people in the United States and an estimated 30-40 million worldwide have, had, or will develop alopecia areata at some point in their lives.

What triggers the condition to start or stop?
Alopecia areata results when the body’s immune system attacks healthy hair follicles by mistake. Alopecia areata is often likened to a “storm of bees” in the form of specific T-cells that attack the hair follicle. Normal hair follicles are hidden from immune reaction because they enjoy a state of immune privilege or protection from autoreactive attack. The collapse of this immune privilege is what allows the swarm of T-cells to attack in alopecia areata. We do not know what activates the autoreactive reaction in alopecia areata but research suggests it is a combination of genetic susceptibility and environmental triggers which may signal changes that confuse the immune system.

Is alopecia areata hereditary?
Hereditary can play a role in the development of alopecia areata. Approximately one out of five persons with alopecia areata report having another family member with the disease. Research suggests there is also a correlation between age of onset and presence of family history. Studies show that those who develop alopecia areata for the first time after the age of thirty are less likely to have another family member with the condition than those who develop alopecia areata before the age of thirty. In cases of identical twins, if one twin has alopecia areata there is 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.

Data from the Alopecia areata Registry, Biobank and Clinical Trials Network (Registry) has shown that family members of those who have had alopecia areata often have hay fever, allergic eczema, or other autoimmune conditions such as thyroid disease, early-onset diabetes, rheumatoid arthritis, lupus erythematosus, vitiligo, pernicious anemia, or Crohn’s disease.

Recent genetic studies performed utilizing samples from the Registry, discovered eight genes that contribute to alopecia areata, one of which has a possible role in the onset of the disease. Many of these are associated to other autoimmune diseases, including rheumatoid arthritis, type 1 diabetes and celiac disease.

What other parts of the body are affected?
In some cases, the nails develop stippling that looks as if a pin had made rows of tiny dents. In a few, the nails are severely distorted. There are a variety of other autoimmune and inflammatory conditions that are often concurrent to alopecia areata. Further studies are needed to evaluate the significance of these associations.

How will alopecia areata affect my daily life?
Alopecia areata is not medically disabling; persons with alopecia areata are capable of normal health. But emotionally, this disease can be challenging, especially for those with extensive disease. One of the purposes of the foundation is to reach out to individuals and families with alopecia areata and help them manage the disease, providing them with thousands of sufficient, well-adjusted, contacted people who have lived with this condition. Some professional support contacts. These volunteers and groups have alopecia areata or are closely associated with someone who does. Support groups further contribute to the cause and treatment of all forms of alopecia areata.

What research is being done?
There is extensive worldwide research focusing on the cause and treatment of all forms of alopecia areata. NAAF is leading this research effort by raising private funds and awarding grants to university centers across the United States, Canada, and Europe, and by working closely with the government to increase the funding and accelerate to a treatment. NAAF has awarded millions of dollars to fund research at over 70 university centers throughout the world and has embarked on a focused Treatment Development Program (TDP).

The TDP drives efficiency and improves research by bringing experts in the fields of hair and skin disease research, clinical care, basic science, immunology, autoimmunity and industry together to distill the latest advances into a work plan for the next, most high-leverage research investments. The focus is now on moving promising targets from basic research discovery to pilot clinical trials. Recent partnerships with industry to test FDA-approved treatments that act on these targets in the alopecia areata population, and investing in the research infrastructure to pave the way for clinical trials.

For more information on current research and the TDP, please visit the NAAF website at www.naaf.org.

Do the Foundations have support groups?
The Foundation sponsors volunteer support groups national and international. These volunteers, or phone contact the NAAF office.

Where can I get help?
The National Alopecia Areata Foundation (NAAF) is the global center for trusted alopecia areata information, research, and support. Located in San Rafael, California, the Foundation is governed by a board of volunteers and endorsed by Basic and Clinical Research Advisory Councils. Our trained staff are committed to NAAF’s mission of researching to find a cure or acceptable treatment for alopecia areata, support those with the disease, and educate the public about alopecia areata. For more information on NAAF’s various Programs and Services, please visit www.naaf.org.

Are treatments available?
There are several treatments that have been approved by the Food and Drug Administration (FDA) for alopecia areata. Contact your health care provider for information on these treatments.

For more information on these treatments, please visit the NAAF website at www.naaf.org.
In addition to this brochure the Foundation has:
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• a brochure that deals with coping
• a few seven-minute DVD “Alopecia Areata: Why My Hair Falls Out?” available to children who need a way to share their feelings about alopecia areata with friends, family, peers, schoolmates, principals, and teachers
• a school guide to aid teachers and parents in dealing with alopecia areata in the classroom
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• a message board that provides a safe place for people to connect with others who understand
• the Ascot Fund, a financial assistance program for individuals who need help purchasing hairpieces
• a cosmetic guide with tips on wigs, makeup tips, camouflage and resources
• the Alopecia Areata Marketplace (www.naaf.org/ marketplace) to provide additional resources for hard to find products for help making life with alopecia areata easier
• a health insurance pad to help with your submission of a claim or appeal
• detailed information on current research, current treatments, and medical information
• annual reports
• specific fact sheets and reprints on various topics
• personal/e-mail pal program

What other information and support does the Foundation provide?

With your help the Foundation can help you, and you can help the Foundation, and you can help others. You can donate by sharing.

with others like you. Talk and listen to people you understand. Know you are not alone. Face the sometimes-hostile world boldly by the strength, comfort, help, friendship, and action as well. The Foundation brings together thousands of people with alopecia areata worldwide to provide information, spur research, and bring an end to this disease. If you have alopecia areata, the Foundation can help you, you can help the Foundation, and you can help others.

Help yourself and others by sharing. When you donate to the Foundation, your money is immediately put to work by encouraging and funding research to improve treatment and find a cure, and in communicating with others about alopecia areata. The combined resources of these with alopecia areata through the Foundation have made tremendously positive contributions to the lives of people with alopecia areata. Help yourself and others today.

What is alopecia areata?

When is the Foundation's annual international patient conference?

Join the Alopecia Areata Registry, Biobank and Clinical Trials Network

The Alopecia Areata Registry, Biobank and Clinical Trials Network is an organized network of centers that identify and register patients with alopecia areata. Relevant research samples are collected and information is catalogued and stored in a central repository. The Registry is a powerful resource of clinical data available to investigators studying the disease and biopharmaceutical companies developing treatments. You can register online at www.naaf.org/registry.

What online services does the Foundation provide?

The Foundation’s newsletter, Beneath the Surface, is distributed bi-monthly. The Foundation also has an active Message Board that offers a safe and nurturing environment for individuals with alopecia areata, as well as family members, friends, support, and guidance. The NAAF website also lists upcoming events, calls to action, and breaking news. The best way to stay involved and informed is to register on the NAAF website at www.naaf.org, and to check the site frequently for updates. You can also follow us on Facebook and Twitter.

When should I become involved with the Foundation?

In numbers, there is more than safety; there is strength, comfort, help, friendship, and action as well. The Foundation brings together thousands of people with alopecia areata worldwide to provide information, spur research, and bring an end to this disease. If you have alopecia areata, the Foundation can help you, you can help the Foundation, and you can help others.

Help yourself and others by sharing. It may save you the only person in the world with alopecia areata, but you are not. Help yourself by sharing

Does the Foundation have a newsletter?

The Foundation’s newsletter, Alopecia Areata News, published four times a year, provides a forum for people with alopecia areata and their friends and families to receive the latest information on activities of the foundation and the community we serve. It enables people with alopecia areata to speak out about the problems associated with the disease and how to deal with them. It contains news about research and treatments, personal stories, cosmetic tips, information on support groups, and a special children’s section called KidNet. We ask that those who wish to receive the newsletter donate to cover the cost.

What other information and support does the Foundation provide?

In addition to this brochure the Foundation has:
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• a health insurance pad to help with your submission of a claim or appeal
• detailed information on current research, current treatments, and medical information
• annual reports
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• personal/e-mail pal program

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