



SUPPORT RESOURCES FOR LIVING WITH ALOPECIA AREATA

Even though 700,000 people in the United States live with alopecia areata, most people who are newly diagnosed don't know someone who has it. If this describes you, it's easy to feel alone. But you don't have to be.

No two people experience alopecia areata (AA) in the same way, but by connecting with others, you can learn about the disease and the impact it can have on you and the people who love you. You can discover different resources and ways of coping, and how what may work for one person may not for another.

SUPPORT GROUPS

Formal [support groups](#), virtual (online) or in-person, are good options for people who want to connect with others who know what AA is and what it is like to live with it. Participating in these groups allows you to meet and interact with others who have been in the same place, whether it is you who has alopecia areata or your child.

For parents, learning that your child has alopecia areata can be devastating. Although it's not a fatal disease or one that causes physical pain, parents and caregivers may worry about the psychological impact of the condition. NAAF offers support groups for parents and caregivers, as well as a [youth mentor program](#), so children can connect with others who also lived with alopecia areata as a child.

Kenna Stephen, a 20-year-old student in Denver, CO, was diagnosed with AA when she was two years old. According to her mother, Heather, Kenna was fine at the time, walking around telling people she didn't have hair. But it was different for Heather. "We were told our child had an autoimmune disease that was incurable. And then we walked out of the doctor's office and we were just alone," she says. Finding the Denver children's support group gave Kenna the chance to be with other children who looked the same and it helped Heather and the rest of the family to learn about the disease and meet others in the same situation, she says.

Kenna experienced hair regrowth so stopped attending the support group, but when her hair fell out again in seventh grade, she joined a group for pre-teens and teens. "That was a super positive experience," she says. "I made a lot of good friends that way."

The Stephen family's experience has gone a full circle. Heather and her husband now run that child support group and Kenna goes back as a mentor. "We want to give back to the community that was there for us the whole time, seeing us through," Heather explains. As for Kenna, "I

think it's cool for those parents and kids to see somebody like me who's been through it. I'm functioning and thriving. It's meaningful for them and it's super meaningful for me."

ONE-ON-ONE SUPPORT

If you aren't comfortable being part of a group or need extra help, NAAF also offers [one-on-one phone support](#) for people with alopecia areata. Trained NAAF volunteers take the time to speak with you and listen to you. Taking advantage of different types of support can be helpful as different issues come up.

CONFERENCES AND EVENTS

Bigger gatherings, such as local community events or the NAAF conferences, give people with alopecia areata an opportunity to get together with others in a more social environment than what support groups offer. The [annual conference](#) also provides information and updates on research and treatments and connections with others who live with the disease. And there's more! The conference offers a fun-filled camp for children from 5 to 17 years, where they can be just one of the kids without feeling like they stand out as they may at home.

NAAF SUPPORT RESOURCES

If you would like to be part of a support group, you can ask your dermatologist if they know of any in your area, or you can participate in [NAAF support groups](#). NAAF offers these both online and in-person, depending on the location.

Get Support: <https://www.naaf.org/find-support/>

Support Groups: <https://www.naaf.org/find-support/support-groups/>

Youth Mentor Program: <https://www.naaf.org/youth-mentor-program/>

One-on-One Phone Support: <https://www.naaf.org/one-on-one-phone-support/>

NAAF Conference: <https://www.naaf.org/conference/>

WHY SHOULD I BECOME INVOLVED WITH NAAF?

There is strength in numbers. NAAF is a grassroots, volunteer-driven organization that brings together millions of people from across the world, all of whom have one thing in common: alopecia areata. Join us in supporting each other, guiding research, and curing this disease. **Your help is essential if NAAF is to achieve these goals.**

Provide help for today and hope for tomorrow by:

- Reading stories from others, so you do not feel alone
- Sharing your own experiences
- Advocating for access and change at the local, state, and federal levels
- Getting or offering support
- [Donating to NAAF](#) to further its work in research and education
- Joining us for the annual Walk For Alopecia or create your own DIY fundraiser
- Receiving the monthly electronic newsletter and other communications
- Participating in webinars and other events listed on NAAF's website
- Attending NAAF's annual patient conference

Connect with us:

[National Alopecia Areata Foundation](#)

65 Mitchell Blvd., Suite 200-B

San Rafael, CA 94903

www.naaf.org

Phone: 415-472-3780

Email: info@naaf.org



NAAF gratefully acknowledges the support for this informational brochure provided by:

