

## SUPPORT RESOURCES FOR LIVING WITH ALOPECIA AREATA



## **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**

www.naaf.org/find-support

#### **SUPPORT GROUPS**

www.naaf.org/find-support/support-groups

#### YOUTH MENTOR PROGRAM

www.naaf.org/youth-mentor-program

#### **ONE-ON-ONE PHONE SUPPORT**

www.naaf.org/one-on-one-phone-support

#### **NAAF CONFERENCE**

www.naaf.org/conference

## **CONNECT WITH NAAF**

NAAF is the voice of the AA community. It serves the nearly 7 million Americans who live with the autoimmune disease, which causes unpredictable, often sudden, and severe hair loss. Many people think of AA as a cosmetic condition, but hair loss can be deeply traumatic. It can cause emotional and economic pain and social isolation. It is not just hair.

As NAAF pushes for AA research, support, and awareness, it also provides 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, raising awareness to reduce stigma, and providing 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!

#### **CONNECT WITH US:**

65 Mitchell Blvd., Suite 200-B San Rafael, CA 94903















NAAF gratefully acknowledges the support for this informational brochure provided by Pfizer and Eli Lilly and Company

# SUPPORT RESOURCES FOR LIVING WITH ALOPECIA AREATA

Even though nearly 7 million people in the United States are affected by 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 she stopped attending the support group, but when her hair fell out again in seventh grade, she joined another group, this time 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 is using their experiences to help others. 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.



www.naaf.org