annual report 2022

NAAF supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata.

GROWTH  RESILIENCE  ADVOCACY  COMPASSION  EMPOWERMENT

table of CONTENTS

04  ...........................................  Letter From the President & CEO, and Board Chair
06  ............................................................  Support & Education
08  ............................................................  Awareness & Advocacy
12  ........................................................................  Community
14  ............................................................  Treatment Development Program
16  ........................................................................  Strategic Plan
17  ........................................................................  Financials
18  ........................................................................  Board of Directors

National Alopecia Areata Foundation
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Dear Friends,

2022 was a watershed year for the National Alopecia Areata Foundation (NAAF) and the community we represent.

The year began with exciting opportunities for the board and new staff leadership to forge a strong partnership and build on the forty-year legacy of NAAF’s mission-focused work. Just three months into the year, the incident at the Oscars ceremony created a global alopecia areata awareness moment like nothing seen before. A key pillar of NAAF’s mission is to educate the public about alopecia areata, so the NAAF community rallied to answer the flood of media inquiries from local and national media outlets, which resulted in major segments on the PBS Newshour, Second Opinion with Joan Lunden, ABC News, CBS News, NPR, and CNN’s online Wellness section.

While we did not choose the circumstances for this sudden awareness about alopecia areata, we seized the opportunity to educate the public and help reduce stigma around the disease.

This wave of awareness could not have been better timed, as in mid-June we shared the news that many had waited a lifetime to hear: the Food and Drug Administration (FDA) announced Olumiant as the first ever drug approved for treatment of severe alopecia areata.

To quote NAAF’s 2022 Impact Report, “This was the culmination of big thinking combined with big action by the NAAF community. It represents the successful outcome of two decades of focused effort by NAAF, the researchers NAAF funds and collaborates with, our industry partners, and our patient advocates – all made possible by NAAF donors.” This is only the beginning as we anticipate more treatment approvals in 2023 and the years to follow. The era of more and better choices for the alopecia areata community has begun.

This incredible news carried us into the aptly titled A Community Reunited, 37th Annual Patient Conference, our first live event since Covid. Nearly 400 attendees gathered in Washington, DC to learn, laugh, grow, advocate, and most importantly, become empowered by connecting - in person - as a compassionate and resilient community.

The year closed with the news that the congressional Omnibus FY 2023 Appropriations bill included language authored by Representative Ayanna Pressley (D-MA), calling for more research into the mental health impact of alopecia areata and studies showing the disproportionate effect of the disease on people of color, specifically women. This language amplifies and cements the importance of alopecia areata as a serious autoimmune disease.

This Annual Report chronicles one of the most important years in NAAF’s history. This is the story of you and NAAF working together – and making real progress – to make life better for all those living with alopecia areata. Thank you for taking this momentous journey with us.

Ann Hollins
Chair, Board of Directors

Nicole Friedland
President & CEO

Nicole Friedland
President & CEO

Ann Hollins
Chair, Board of Directors

The Food and Drug Administration (FDA) announced Olumiant as the first ever drug approved for treatment of severe alopecia areata.
1453 Community Members participated & are supported by 136 NAAF Support Group Meetings around the country.

133 Mentors & 65 Mentees participated in NAAF’s Youth Mentor Program resulting in 35 matches.

In 2022, NAAF started a new teen support group for girls ages 12-17.

NAAF welcomed 412 attendees at our first in-person annual patient conference since 2019.

"NOT ONLY DOES THE SUPPORT GROUP HELP THE MEMBERS THAT ATTEND, BUT IT ALSO HELPS ME LEARN AND GROW."

Harris Roach
Support Group Leader, Atlanta, GA

"WE CREATE COMMUNITY & EMPOWER PEOPLE LIVING WITH ALOPECIA AREATA"

181 FIRST TIME ATTENDEES
Representing 33 states and 5 foreign countries.

50 SCHOLARSHIPS
Received by 33 adults and 17 children to attend NAAF’s Annual Patient Conference
Alopecia areata received record media attention following the 2022 Academy Award ceremony. NAAF responded immediately with an awareness campaign entitled “#AlopeciaAreataIsNoJoke.”

From small local news outlets to the PBS NewsHour, NAAF representatives candidly discussed the disease and used the spotlight to better educate the public about alopecia areata.


NAAF social media engagement skyrocketed as we doubled the amount of followers on Instagram.
Increased funding for the National Institutes of Health allowing growth of the government’s alopecia areata research portfolio

Passage of legislation which will provide insurance coverage for wigs

Passage of “The Safe Step Act” which will reform step therapy

ORY LEGISLATIVE PRIORITIES

351 Legislative Liaisons and 13 Legislative Mentors, young people interested in the legislative process but not yet old enough to become a Legislative Liaison, participate in 78 in-person and virtual meetings with their elected officials.

3 days of advocacy on Capitol Hill feature Legislative Liaisons and Mentors advocating with the American Academy of Dermatology Association and the Coalition of Skin Diseases, as well as meet with their legislators for NAAF’s Hill Day.

$2.5 billion increase in funding is approved by Congress for the National Institutes of Health. Of that, $685.87 million, a $29.77 million increase over the previous year, is allocated for the National Institute of Arthritis and Musculoskeletal and Skin Diseases which has an alopecia areata research portfolio.

The Congressional Omnibus FY 2023 Appropriations bill includes special language authored with NAAF’s assistance by Representative Ayanna Pressley. The included language is important as it demonstrates Congress is not only serious about finding new treatments and a cure for alopecia areata but learning more about the mental health impact the disease has, and its potentially disproportionate effect on minority communities. The language also buttresses the argument that alopecia areata is not simply a cosmetic condition but a serious disease worthy of insurance coverage for wigs and treatments.

“Being a Legislative Mentor is a meaningful role for me as it allows me to make my voice heard on a crucial healthcare topic while expanding my skills and capabilities in the political, governmental, and policy fields.”

Joshua Levine
NAAF Legislative Mentor, Needham, MA
One thing about alopecia areata I wish my classmates knew is I am not contagious. I am just like them.

Abby Chan

It makes me happy when my classmates treat me just the same as everyone else.

Caroline Robberson

The mental toll alopecia areata can take on a person is huge. I, along with many other young people, have had to mature and adjust in ways that a teenager shouldn’t have to worry about. So please think before you judge ANYONE for what they look like.

Jenna Funtanilla

This could happen to anyone, so don’t make me feel less than anyone else. I’m dealing with it the best I know how.

Donita Ford

There are positive things that come with alopecia. For one, the community comprises resilient and incredibly kind people of all ages.

Alison Lee

Living with alopecia areata is a huge part of mental and total health, so I would ask my doctor to please don’t be puzzled or dismissive when your patients mention it. Also, wigs and alopecia areata treatments should be covered by insurance, and we need to make that happen!

Lisa Lai

It’s okay if I’m not feeling brave. This is a war, not just a single battle. I have good days and bad days, but the bad days are just as necessary as the good. When I’m sad, it’s okay to cry.

Keira Kirk

Just because I’m okay with my hair loss some days it doesn’t mean I’m okay with it every day. Some days can be really hard and on those days, I’d really love a hug!

Georgia Van Cuylenburg

One thing about alopecia areata I wish my dermatologist knew is: How common hair loss is within the Black community.

Ebony Jean

Being a woman with alopecia areata has given me a unique and diverse outlook on life. It has allowed me to see the world from a different angle and bring a creative perspective to the workplace.

Noelle Arena

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Noelle Arena
NAAF led the charge to reach this milestone by working with pharmaceutical industry partners, convening key opinion leaders in alopecia areata research, and connecting the patient community with clinical trials and other research studies. Research has been a key mission pillar for NAAF from its inception, with basic science and clinical leaders from NAAF’s Research Advisory Council leading the way to advancing discoveries and bridging the gap to clinical applications. The NAAF community deserves credit as well, participating in the clinical trials and advocating before the FDA in 2017 for the tremendous need for treatments.

Progress continues. Other industry leaders in drug development have completed late-stage clinical trials on two other JAK inhibitors: ritlecitinib from Pfizer and deuruxolitinib from Concert Pharmaceuticals (recently acquired by Sun Pharma). A second treatment approval is anticipated in 2023, and a third is likely in 2024. New clinical trials are gearing up, including phase 2 trials for medications targeting different inflammatory processes, as well as trials for JAK inhibitors in children and adolescents. We are at the very beginning of a new era of treatments for alopecia areata.

NAAF grants continue to support research into understanding the mechanisms underlying the disease process in alopecia areata, as well as the impact and burden of the disease to those living with it. In fact, NAAF was proud to launch a collaborative Pediatric Alopecia Areata Challenge Grant program with the Pediatric Dermatology Research Alliance (PeDRA) in 2022 to advance research in pediatric alopecia areata. We look forward to continuing this program and learning the results from this new research initiative.

Looking back, we salute the research pioneers whose critical research accomplishments led to the first treatment approval. Looking ahead, NAAF’s research focus and Treatment Development Program will continue to drive innovation through grants, partnerships, and the essential voice of the alopecia areata community and its desire for multiple safe and effective treatments.
At the end of 2022, the NAAF leadership team and board finalized a 3 Year Strategic Plan, sharpening focus on 4 primary goals and 9 key objectives that align with NAAF’s mission, vision and values. These goals reflect NAAF’s plan to evolve and grow with the changing landscape of care for, and needs of, the alopecia areata community. The plan was built with extensive stakeholder feedback, gathered through surveys and interviews, and stewarded by a Board Task Force. We thank the community for their participation, and we are pleased to share the 2023-2025 Strategic Goals and Objectives.

Our Mission

NAAF supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease and educates the public about alopecia areata.

Our Vision

An empowered community with a choice to embrace or live free of alopecia areata.

Our Values

Growth
Resilience
Advocacy
Compassion
Empowerment

Our Goals & Objectives

Increase Focus on New Treatments

Expand advocacy tools & strategies to increase access & affordability
Identify and meet evolving needs from NAAF’s research program

Expand Community

Increase patient programs effectiveness
Increase reach & diversity
Raise awareness of alopecia areata in the general public to reduce stigma

Build Operational Excellence

Build capacity of staff team
Increase volunteer leadership & engagement opportunities
Increased efficiencies through improved internal systems, policies, & data collection

Elevate Development Strategies to Power Mission Impact

Grow revenue by building strategic relationships to support bold new development activities

Financial Highlights

There is strength in numbers, especially those demonstrating our commitment to support, awareness & research.

Total Income: $2,349,751
Total Expenses: $2,428,410

Ending Net Assets

$1,862,966

The completed audited financial statements are available on the website at www.naaf.org.
BOARD OF DIRECTORS

NAAF is governed by a volunteer Board of Directors and advised by its Research Advisory Council and Scientific and Medical Advisory Task Force, both comprised of leading experts in alopecia areata research and treatment.

NAAF demonstrates excellence in governance, accountability, and transparency by earning the highest rating on the following industry standards: the National Health Council Standards of Excellence; the Better Business Bureau – Wise Giving Alliance Standards for Charity Accountability; and Candid (formerly GuideStar).