

annual report 2022

National Alopecia Areata Foundation



National
Alopecia Areata
Foundation

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

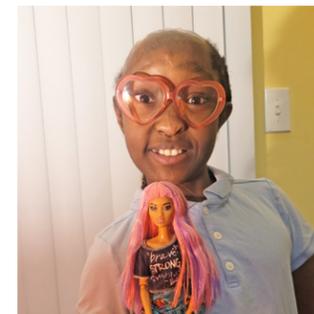


EMPOWERMENT



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



a watershed year for the community

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.



Nicole Friedland
President & CEO

Ann Hollins
Chair, Board of Directors

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



The Food and Drug Administration (FDA) announced Olumiant as the first ever drug approved for treatment of severe alopecia areata.





support & education

WE CREATE COMMUNITY & EMPOWER PEOPLE LIVING WITH ALOPECIA AREATA

“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



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.



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



awareness & advocacy

WE RAISE AWARENESS & EDUCATE THE PUBLIC ABOUT ALOPECIA AREATA



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.

11 billion impressions, 3 times the number for 2021, were created by **4,270 media mentions** in such high-profile outlets as MSN.com, The New York Times, Healthline, Yahoo! Japan, Daily Mail, WebMD, Medical News Today, Yahoo! News, The Washington Post, New York Post, USA Today, The Independent, NBC News, and BuzzFeed.

NAAF social media engagement skyrocketed as we doubled the amount of followers on Instagram.





OUR LEGISLATIVE PRIORITIES

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

awareness & advocacy

WE RAISE PUBLIC AWARENESS & ENHANCE PERCEPTION OF ALOPECIA AREATA

"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

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.



NAAF'S
FIRST HILL
DAY SINCE
2019!

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.



Alopecia forces us to grow beyond worrying about what others may think of our appearance and helps us learn that true happiness comes from pursuing the things that give our lives real meaning. Embrace life and all it offers...don't let the anxiety of appearance hold you back from doing something amazing!

George Perry



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

Caroline Robberson



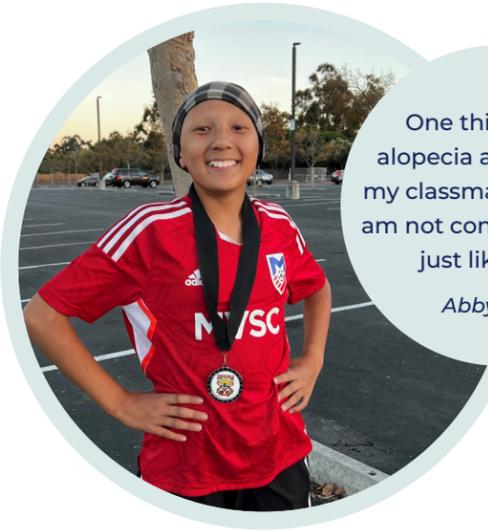
There are positive things that come with alopecia. For one, the community comprises resilient and incredibly kind people of all ages.

Alison Lee



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

Ebony Jean



One thing about alopecia areata I wish my classmates knew is I am not contagious. I am just like them.

Abby Chan



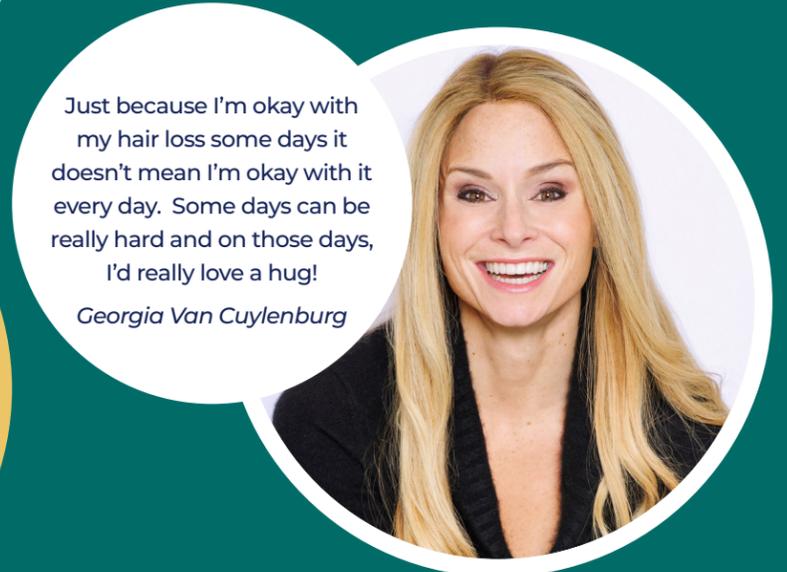
It's okay if I'm not feeling brave. This is a war, not just a single battle. I have good days and bad days, but the bad days are just as necessary as the good. When I'm sad, it's okay to cry.

Keira Kirk



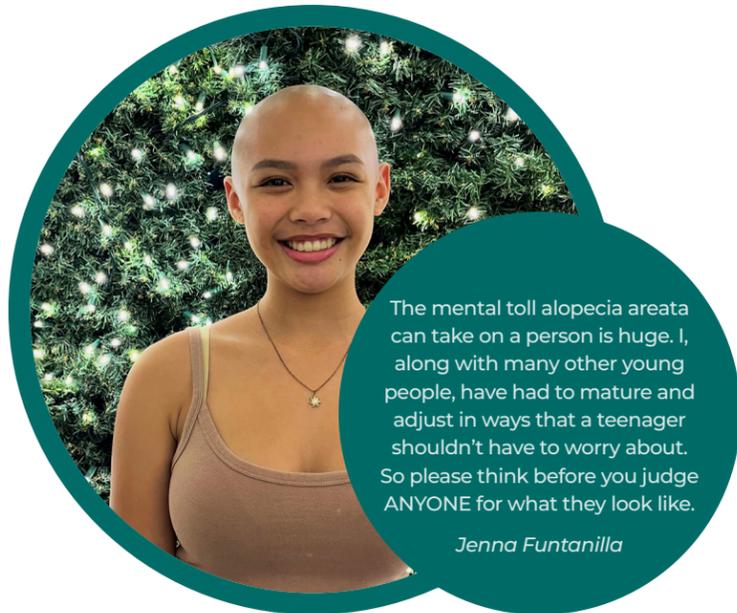
Living with alopecia areata is a huge part of mental and total health, so I would ask my doctor to please don't be puzzled or dismissive when your patients mention it. Also, wigs and alopecia areata treatments should be covered by insurance, and we need to make that happen!

Lisa Lai



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



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



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

community

treatment development

WE SUPPORTED RESEARCH TO FIND A CURE OR ACCEPTABLE TREATMENT AND ESTABLISH THE BURDEN OF DISEASE

2022 marked the arrival of the first medication approved by the Food and Drug Administration (FDA) for the treatment of severe alopecia areata. Olumiant (baricitinib) from Eli Lilly and Company received its approval on June 13, 2022 - a moment to look back on how NAAF's research efforts brought us here and to look ahead at what is still to come.



Led by Dr. Angela Christiano and based on studies of samples from the National Alopecia Areata Registry, research describing the genetics underlying the development of alopecia areata were published in the journal Nature in 2010. Following this breakthrough discovery, NAAF launched its Treatment Development Program to focus all available resources and partnerships to drive the research community towards treatment innovation. NAAF's support of the development of a mouse model of alopecia areata led to understanding of the disease process and the inflammatory attack on hair follicles via the JAK-STAT pathway. Noting this discovery, Drs. Britt Craiglow and Brett King tested a new drug, a JAK inhibitor, in a patient with alopecia areata, and were the first to publish a report demonstrating the effectiveness of a JAK inhibitor on hair regrowth in 2014. Since then, interest and innovation around JAK inhibitors has continued to grow, with an expanding list of approved medications for multiple conditions - including for alopecia areata in 2022.

The New York Times

F.D.A. Approves Alopecia Drug That Restores Hair Growth in Many Patients

The drug, made by Eli Lilly, is already used for rheumatoid arthritis, and could be followed by two more drugs from other companies.

- 500** COMMUNITY MEMBERS
participate in a NAAF survey on living with alopecia areata, interactions with healthcare providers, and treatment experience
- 2** PEDIATRIC ALOPECIA AREATA GRANTS
awarded investigating the disease impact on adolescents & their families as well as the immune cell profile in pediatric alopecia areata patients
- 7** RESEARCH SURVEYS
from academic investigators shared with community for data collection on the burden of living with alopecia areata
- 5** TRAVEL AWARDS
to young investigators presenting research on alopecia areata at professional conferences

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.

2023 - 2025 STRATEGIC PLAN

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

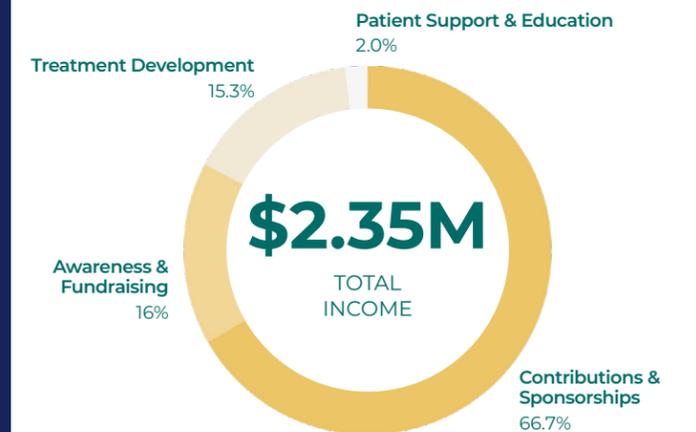
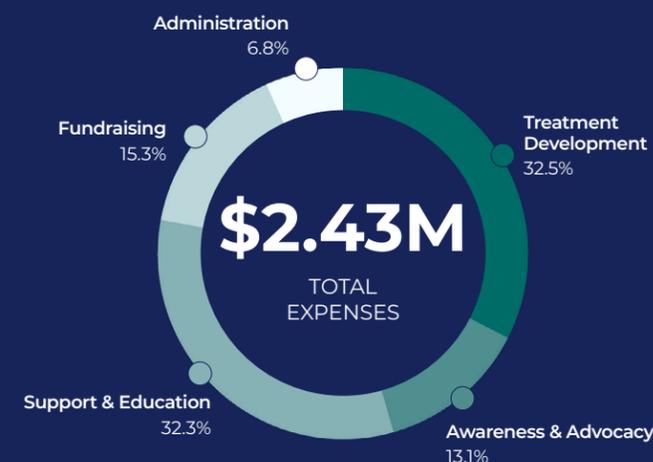


FINANCIAL HIGHLIGHTS

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).

2022 directors

Ann Hollins, Chair

Bonnie Chong, Vice Chair

Jim O’Connell, Chief Financial Officer

Simon Rubenstein, Secretary

Bob Flint

Tyrone Folliard-Olson

Ann S. Hedges

Salman Hussain

Jonelle Massey

Maureen McGettigan

Deirdre Nero

Ron Saca

Amanda Wagner

Wendy Yu

Nicole Friedland, President & CEO

founding chair

Vera H. Price, MD



NATIONAL ALOPECIA AREATA FOUNDATION

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

415-472-3780 · info@naaf.org

www.naaf.org



National
Alopecia Areata
Foundation