



2023

NATIONAL ALOPECIA AREATA FOUNDATION

# ANNUAL REPORT

## Dear Friends,

In 2023, the National Alopecia Areata Foundation (NAAF), powered by our amazing community, built on the momentum from NAAF's 40+ year history, and reached new heights in treatment, research, support, and advocacy.

NAAF has long been the catalyst for breakthrough alopecia areata research, laying the scientific groundwork that has accelerated treatment innovation. This year we saw the second treatment approved for alopecia areata by the Food and Drug Administration (FDA) when LITFULO™ was made available to patients 12 years and up. This is a tremendous advancement for youth living with alopecia areata.

We remain committed to empowering our community with more choices. We anticipate more treatment approvals in the coming years and have begun the important advocacy work to ensure access and affordability of these new treatments, as well as wigs, and other choices that our community members make on their alopecia journey.

This year, NAAF welcomed alopecia areata treatment pioneer, Brett King, MD, PhD, to the Board of Directors. Dr. King's revolutionary use of the Janus kinase (JAK) inhibitor in dermatology revealed the utility of this class of medicines for the treatment of alopecia areata, paving the way for development of the first reliably effective therapies for the disease. His expertise is invaluable as we enter this era of new treatment choices.

NAAF also took important steps to grow our organization's impact and expand our community. From our revitalized patient conference to our new and improved website at [www.naaf.org](http://www.naaf.org), NAAF is a leading source of support and information about alopecia areata. NAAF's highly viewed "You Are Not Alone Empowerment and Education" webinar series has reached 35,000+ viewers and is providing treatment updates and strategies for living better with alopecia. The webinars are now available with translatable captions, making this critical information available to many more.

NAAF brings together the alopecia areata community, working with patients and families, medical care professionals, researchers, donors, and other advocacy organizations to drive progress and change. This was demonstrated at the inaugural Walk For Alopecia, which engaged thousands nationwide in shining a bright light on alopecia areata. Over 3,000 members of the community walked in 26 states, generating incredible awareness and raising critical funds to power our mission impact. In the same month, we held our largest ever Day on Capitol Hill, where community members advocated for legislation that will improve the lives for those with the disease.

This Annual Report tells the story of a resilient community working together to drive research breakthroughs, increase access to treatments, support those on the journey, and make life better for all those living with alopecia areata. We are so grateful to all of you who made this progress possible.

**ann hollins**

CHAIR, BOARD OF DIRECTORS

**nicole friedland**

PRESIDENT & CEO



## 2023 Board of Directors

**Ann Hollins**  
*Chair*

**Bonnie Chong**  
*Vice Chair*

**Jim O'Connell**  
*Chief Financial Officer*

**Simon Rubenstein**  
*Secretary*

**Shamsha Damani**  
**Tyrone Foliard-Olson**

**Ann S. Hedges**

**Brett King, MD, PhD**

**Jonelle Massey**

**Maureen McGettigan**

**Deirdre Nero**

**Ron Saca**

**Wendy Yu**

**Nicole Friedland**  
*President & CEO*





# Empowering Choices by Providing Critical Support Services

Responding to the availability of newly approved treatments and other advancements in care, NAAF elevated services to the alopecia areata community in numerous ways during 2023.

## DOCTOR FINDER

The Doctor Finder was launched to help those with alopecia areata locate a dermatologist in their own community who is not only accepting new patients, but also has the expertise needed to properly manage their autoimmune disease. **For more information, visit [naaf.org/doctor-finder](https://naaf.org/doctor-finder).** Special thanks to Eli Lilly & Co. and Sun Pharma for their support of this program.

## “YOU ARE NOT ALONE” WEBINAR SERIES

*“Thank you - so helpful in providing hope to people who desperately need it and for their families.”*

This series covers a wide range of topics including emerging medical treatments for adults and children, clinical trials, wigs and insurance, and psychosocial support on topics such as bullying and confidence building. **For more information, visit [naaf.org/webinars](https://naaf.org/webinars).** Special thanks to Pfizer, Eli Lilly & Co., and Sun Pharma for their support of this program.

## 38<sup>TH</sup> ANNUAL CONFERENCE

*“As a parent, this conference and camp allowed me to connect with others who have walked similar journeys. It is honestly our family’s Disney World.”*

Reaching New Summits Together, NAAF’s annual conference welcomed 450+ attendees to Denver—a 10% increase over 2022! Underscoring the importance of representation, 57% of session presenters identified as persons of color. Financial assistance for attendees was increased by 42% over the prior year thanks to the support of NAAF donors. Special thanks to Pfizer, Eli Lilly & Co., and Sun Pharma for their support of the conference.



## YOUTH MENTOR PROGRAM

*“What a great match! My daughter Ava is a competitive cheerleader, and Samantha is a cheer coach. Ava sees herself as a younger version of Samantha. She’s not only been helpful in building confidence, but she’s been so helpful in figuring out tips and strategies for managing alopecia as a young athlete. We can’t express enough how grateful we are for this program.”*

The NAAF Youth Mentor Program connects children living with alopecia areata to dedicated young adult mentors. The goal is to form lasting bonds while providing support and guidance for dealing with the day-to-day challenges stemming from alopecia areata.

In 2023, 154 Mentors and 85 Mentees were part of the program, resulting in 54 new matches. Special thanks to Eli Lilly & Co. for their support of this program.

## SUPPORT GROUPS

*“As a support group leader for NAAF, I am privileged to provide personal, emotional, and social support to people who are coping with their alopecia diagnoses, and in doing so, I am able to strengthen my own confidence and sense of self as someone with alopecia as well!”*

NAAF has support groups all over the world that provide a safe, comfortable and trusting environment in which people can share their personal experiences with this challenging disease. More than 80 volunteers lead 64 support groups around the United States & Canada.

In 2023, 4 new groups were added as well as a new virtual teen group for boys ages 12-17. Special thanks to Eli Lilly & Co. for their support of this program.

# Empowering Choices Through Awareness and Advocacy



NAAF debuted an updated and refreshed website featuring:

- ✓ Easier navigation
- ✓ Quicker means of finding support
- ✓ Updated content
- ✓ The new Doctor Finder



In June 2023, NAAF broke the news of a second FDA-approved treatment for alopecia areata, and the first for children ages 12 and up.



NAAF social media reached millions across multiple channels during 2023, with an engagement rate that is 215% better than the industry standard!



Alopecia Areata Awareness Month saw 960 media mentions in 2023 – 3 times the previous year!



1,400+ members of the alopecia areata community used NAAF's new portal to send communications to their elected officials urging they co-sponsor federal legislation which will reclassify wigs as durable medical equipment making them eligible for Medicare coverage. [Go to naaf.org/wigs](https://naaf.org/wigs) and make your voice heard in under 60 seconds!



Wig coverage bills were introduced in Maryland and Massachusetts, with work proceeding to introduce similar legislation in California and other states in 2024.



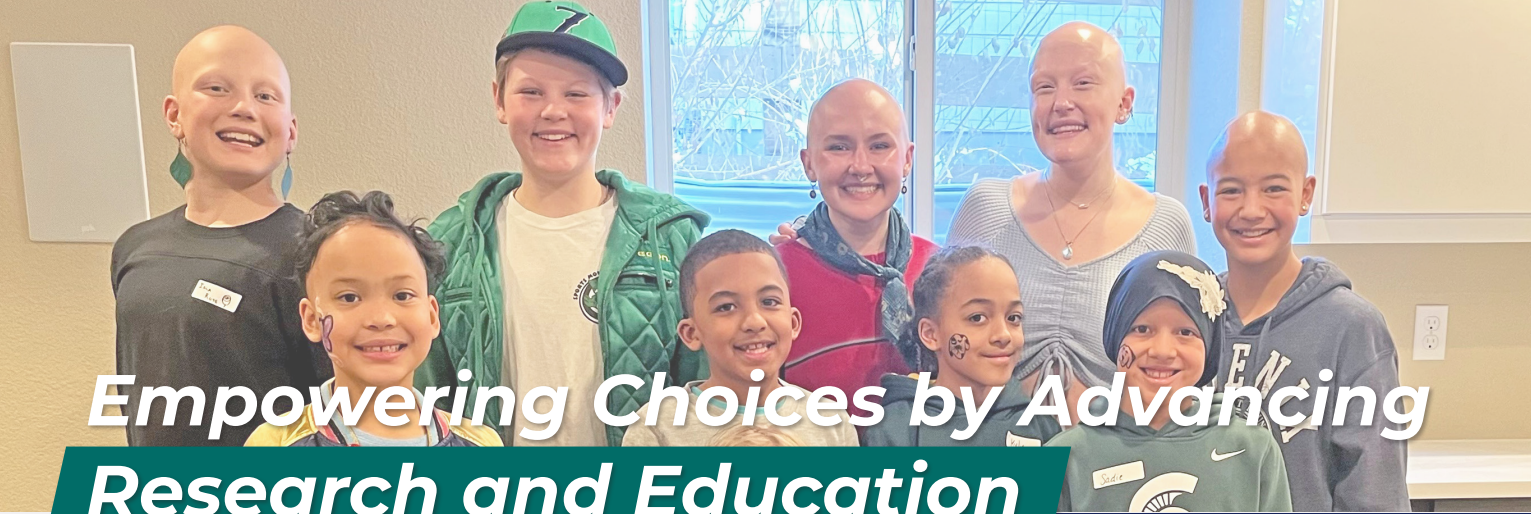
Legislative Liaisons and Legislative Mentors, family members and NAAF staff, met congressional representatives and senators at NAAF's first full-scale Day on Capitol Hill in 4 years, resulting in 8 new co-sponsors for the wig coverage bill in the House of Representatives. NAAF advocates also participated in the planning and execution of the Coalition of Skin Diseases' Hill Day, making our legislative voice even louder in Washington.

“Thank you for letting me have the chance to be a Legislative Mentor. It has been such an amazing opportunity so far and I can't wait to try to find more ways to help out alopecia patients.”

**Stephanie M.**

Age 12





# Empowering Choices by Advancing Research and Education

Choice in treatment is driven by investment in alopecia areata research and integrating new therapies into patient care. Those diagnosed with alopecia areata today have options to consider, an improvement over just a few years ago.

## ADVANCING RESEARCH

NAAF continued to promote and support research focused on alopecia areata through its 2023 grants program. Research dollars supported new investigations into the underlying biology of the disease and its impact on patients, in addition to encouraging young researchers in the field. NAAF continued its partnership with the Pediatric Dermatology Research Alliance, awarding two new Pediatric Alopecia Areata Challenge grants. In addition, NAAF made three new research awards, funding studies to examine a range of topics, from genetics to microneedle patches for drug administration, to the impact of the disease in underserved communities. By supporting new research into alopecia areata, NAAF is paving the way for future advancements in understanding and managing the disease.

## ADVANCING EDUCATION

Patients are learning about the availability of approved treatments and dermatologists are learning about them as well. NAAF launched two strategic partnerships in the area of medical education in 2023 to improve knowledge among healthcare providers about the new treatments. Partnering with Clinical Care Options, a continuing medical education provider, and *The Dermatologist*, a print publication and website, NAAF expanded the availability of opportunities for professionals to learn more about treatment options for alopecia areata.

NAAF Student Internship Awards support students (undergraduate, graduate, medical), residents, or fellows interested in conducting research focused on alopecia areata. The goal is to enable promising young scientists and physicians to hone their research skills and go on to become investigators focused on improving the lives of those living with alopecia areata. NAAF Travel Grants support early career researchers attending scientific conferences or meetings to present accepted alopecia areata-related abstracts as talks or posters.

## INDUSTRY PARTNER PROGRAM

NAAF is grateful to the following members of the Industry Partner Program (IPP) whose support benefits alopecia areata programming and research. The IPP drives efficiency and improves research by connecting biopharmaceutical companies with the alopecia areata community to advance understanding of the patient lived experience and accelerate discovery.

### DIAMOND PARTNER



### GOLD PARTNERS



### BRONZE PARTNERS



### COPPER PARTNER



## GRANTS AWARDED IN 2023

Natalie Artzi, PhD · Jamil R. Azzi, MD, PhD · Brigham and Women's Hospital  
*Use of microneedles for the management of alopecia areata*

Zhenpeng Dai, PhD · Columbia University Irving Medical Center  
*Identification of autoantigen epitopes in alopecia areata by T-Scan*

Michal Linial, PhD · The Hebrew University of Jerusalem  
*The genetics of alopecia areata: Integration of population studies and clinical data*

Thy Huynh, MD · University of Mississippi Medical Center  
*Elucidating psychological well-being and access to support in families of children with alopecia areata patients in underserved Mississippi communities*

## 2023 STUDENT INTERNSHIP & TRAVEL AWARDS

Angela Yang · Northwestern University

Megan Mukenge · Wake Forest University

Ilhan Esse · University of Minnesota

Eden David · Icahn School of Medicine at Mount Sinai

Eric Xia · Boston University

Helen Zhang · Brown University

Katelyn Rypka & Ora Raymond (joint award) · University of Minnesota

Betty Nguyen · World Congress of Dermatology, Singapore

Isaac Li-Chi Chen · PeDRA Annual Conference, Atlanta



# Empowering Choices by Bringing Our Community Together

2023 was the inaugural year of the Walk For Alopecia, NAAF's first nationwide fundraising and awareness campaign.

On September 30, the finale of Alopecia Areata Awareness Month, thousands of members of the alopecia areata community across the country stepped off on the inaugural Walk For Alopecia™ to drive research for better treatments and a cure, increase support for individuals and families living with alopecia, to advocate, and to end stigma. For more information, visit [naaf.org/walk](https://naaf.org/walk).

**\$619K** FUNDS RAISED

**3,000** WALKERS IN 26 STATES

**610** REGISTERED FUNDRAISERS  
60% NEW TO NAAF

**138** REGISTERED TEAMS

**221** MEDIA MENTIONS  
IN 10 MAJOR MARKETS IN 26 STATES

## NATIONAL SPONSORS







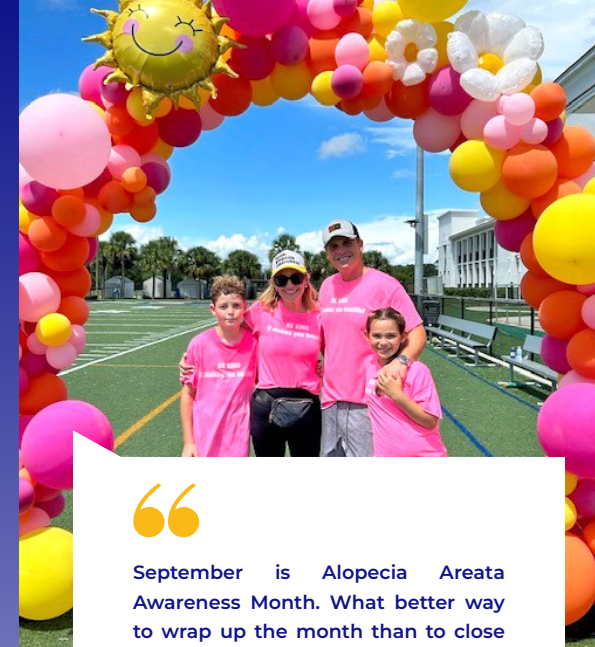
Excitement started building with the nationwide announcement in May to the Walk kickoff at the NAAF Patient Conference in June and throughout the summer. The momentum continued into August with the virtual kickoff and at the special live Instagram rally with Grammy winner Molly Tuttle, to Walk Day with everyone participating across the country while sharing their stories on social media. Every step resulted in empowerment, support, community, hope, fun, and awareness.

Check out the Walk For Alopecia™ highlights on [YouTube](#) and [Instagram](#).

Thank you everyone who stepped up for this inaugural event!

Together, we let the world know that alopecia areata is more than just hair!

[www.naaf.org/walk](http://www.naaf.org/walk)



“

September is Alopecia Areata Awareness Month. What better way to wrap up the month than to close the last day of September with a walk. This is for the nearly 7 million people with alopecia in the US and the millions more around the world. They get to witness first-hand the strength of the alopecia community. Whether we are here today for ourselves or a loved one—this is a community of love and support.

Linda T.

“

I have a lot of friends and family members supporting me at the Walk For Alopecia. I hope more people learn about alopecia and one day there will be a cure. But for now, I'm going to rock my look- with or without hair. With or without a hat or a wig. I am me.

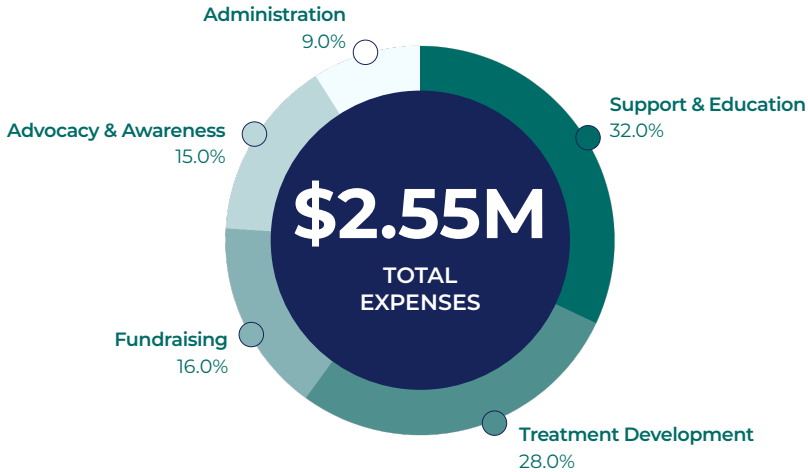
Alexa C.  
Age 10



# Financial Highlights

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

Total Expenses: \$2,545,046 | Total Income: \$3,467,262



## Ending Net Assets: \$922,000

The completed audited financial statements are available on the website at [www.naaf.org](http://www.naaf.org).

NAAF is a private, tax-exempt, nonprofit organization pursuant to Section 501(c)(3) of the Internal Revenue Code with Federal Tax ID# 94-2780249. All gifts and donations are tax deductible in accordance with IRS regulations.

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; and Candid’s Platinum rating (formerly GuideStar). In 2023, NAAF received a four-star rating from Charity Navigator, the highest possible rating.



### CONNECT WITH US



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

415.472.3780

info@naaf.org

www.naaf.org