



Dear Friends,

Your support of the National Alopecia Areata Foundation™ (NAAF™) and the alopecia areata community is fueling an incredible journey of hope, impact, and transformation! In the past three years, we have witnessed unprecedented progress that has ignited a movement and changed the world for people living with alopecia areata.

Prior to 2022, there were no Food and Drug Administration (FDA) approved treatments for alopecia areata. Since then, we have celebrated the FDA approval of three groundbreaking treatments for severe disease! This is a lifechanging achievement for NAAF and those we serve. We have helped drive this progress through support for mouse model research, insights from the National Alopecia Areata Registry, and the discovery of disease genomics.



Today, multiple potential new treatments are in clinical trials. NAAF is investing more in research, and this year, launched an Early Career Award grant to attract the best and brightest young researchers to the field. The National Institutes of Health (NIH) is funding a research study on a non-JAK inhibitor that may be effective for individuals with both alopecia areata and allergic conditions. Scientists and industry leaders are investing in alopecia areata to identify new treatments that will bring more choices.

However, we still have much to do to drive our movement forward! Currently, there is no FDA-approved treatment for children under 12 or for mild to moderate disease. The level of funding for alopecia areata research by the NIH, even including the study mentioned above, is insufficient given that the disease impacts almost 7 million Americans. We have work to do to ensure that newly approved drugs-and wigs as medical equipment—are accessible and affordable for our community.

NAAF is taking essential steps to grow our organization's impact and expand our community, working with patients and families, healthcare professionals, researchers, donors, and other advocacy organizations to drive progress and change. For the first time, we are living in a rapidly changing treatment landscape, and NAAF must reach more community members with the critical information that helps families make the best choices for themselves and their loved ones.

Just a few examples of how we're addressing this need include:

- NAAF's You Are Not Alone webinar series 64,000 views and counting!
- Reinvigorated Annual Conference and Children's Camp
- Nationwide success of the 2nd Annual Walk For Alopecia[™]
- Increasing policy influence through NAAF's "It's Not Just Hair" advocacy campaign

Since 1981, we have worked with our resilient community to accelerate research breakthroughs, increase access to treatments, support those on their 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.

From the beginning and throughout the decades, we have been-and always will be-STRONGER TOGETHER.

ann hollins

CHAIR, BOARD OF DIRECTORS

Al The nicole friedland PRESIDENT & CEO

2024 **Board of Directors**

Ann Hollins, MBA, Chair Tyrone Folliard-Olson, JD, MA, Vice Chair Jim O'Connell, Chief Financial Officer Bonnie Chong, JD, Audit Chair Maureen McGettigan, MBA, Secretary Lisa Bard Levine, MD, MBA Shamsha Damani, MBA, MSLS David Granson, MBA Ann S. Hedges, MFA Brett King, MD, PhD Jonelle Massey, LPC, MA, NBCC Deirdre Nero, JD **Simon Rubenstein** Ron Saca Wendy Yu. MS Nicole Friedland, President & CEO

StrongerTogether By Providing Critical Support Services





NAAF continued to elevate services to our community members throughout 2024, providing resources to access the newly approved treatments and other tools for those living with alopecia areata.

"YOU ARE NOT ALONE" WEBINAR SERIES

"Thank you for doing these. They sincerely help my feelings of being alone in this! I find listening to the webinars enables me to learn more about the disease and know that there are many others who have it."

— Anonymous webinar participant

This series covers a wide range of topics, including emerging medical treatments for adults and children, clinical trials, wigs and insurance, psychosocial support, and topics such as bullying and confidence building.

For more information, visit <u>naaf.org/webinars</u>.

Special thanks to Pfizer, Eli Lilly & Co., and Sun Pharma for supporting this program.

ALOPECIA AREATA SCHOOL GUIDE

In 2024, NAAF unveiled its new <u>Alopecia Areata School</u> <u>Guide</u> to provide useful information to help parents, families, teachers, and school administrators.

For more information, visit <u>naaf.org/schoolguide</u>.



39TH ANNUAL NAAF CONFERENCE & CHILDREN'S CAMP

"To get the opportunity to watch our daughter walk into the conference hotel at 7 years old and see so many people that looked like her was extraordinary! That weekend, her confidence visibly grew; we connected with families just like ours, learned about several new resources, gained insight into new treatment options being developed for younger age groups, and were able to talk with our federal representatives to advocate for legislation on helping wigs to be covered by insurance. It was an unforgettable weekend!" — Leslie J.



Stronger Together, the theme of NAAF's Annual Conference and Children's Camp held in Washington, DC, welcomed 600+ attendees, a 24% growth over the previous year. Reflecting the broad representation within the alopecia areata community, 40% of attendees identified as persons of color. Financial assistance was increased by 30% over the prior year thanks to the support of NAAF donors.

Special thanks to Pfizer, Eli Lilly & Co., Sun Pharma, the Laffey-McHugh Foundation, AbbVie, Mattel, Nektar Therapeutics, and Sanofi for supporting the Conference and Camp.

YOUTH MENTOR PROGRAM

The NAAF Youth Mentor Program connects children 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 the autoimmune disease. "I was

In the summer of 2024, NAAF successfully launched a modernized, automated application designed to streamline the process of connecting mentors with interested youths. Within just three months of its launch, 23 mentees were paired with their new mentors in a matter of days, highlighting the efficiency and impact of this innovation. Nearly 80 families sought to connect their children or teens with a mentor throughout the year, demonstrating the growing demand and positive response to this valuable program.

"I wanted my son to realize that he is a 'normal person' no matter what his hair looks like. He felt ugly and thought he was the only one who had alopecia until he met his mentor."

Arami Y.

Special thanks to the TJX Foundation for their support of this program.

SUPPORT GROUPS

"As someone who has had alopecia for over 45 years, as well as having other family members with alopecia universalis, NAAF was there when my family needed support. I want to be able to give back and be there for others if they need someone to talk to in their time of need."

— Annette P.

With more than 30 active support groups across the country, NAAF offers a blend of in-person meetups and online support to help individuals with alopecia areata and their loved ones feel seen, supported, and part of a compassionate community.

04 • 2024 NAAF ANNUAL REPORT • 05

stronger TOGETHER

Through Awareness & Advocacy







In July 2024, NAAF broke the news of a third treatment for severe alopecia areata, LEQSELVI[™], being approved by the Food and Drug Administration.



In 2024, Alopecia Areata Awareness Month saw nearly 1,000 media mentions—a 40% jump over 2023 reaching over 540 million people across multiple channels!



Senior NAAF staff met with leaders of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) to build a more productive partnership. Also, NIAMS Director Dr. Lindsey Criswell addressed the NAAF conference. In 2024, NAAF completed a strategic review of its advocacy program which acknowledged the exceptional efforts to date as the voice of the alopecia areata community.

A strong go-forward plan was established focusing on educating decision makers about community needs and driving an alopecia areata-specific agenda that will increase investment in research and access and affordability of treatments and wigs.

The 2024 NAAF Day on Capitol Hill resulted in 32 house members and 5 senators cosponsoring legislation to reclassify wigs as durable medical equipment to be covered by Medicare. Many thanks to Pfizer and Sun Pharma for their support of NAAF's advocacy program in 2024.

More than 2,300 members of the alopecia areata community employed the easy-to-use NAAF portal to send over 7,000 communications to their elected officials urging they also co-sponsor this crucial legislation. **Visit** <u>naaf.org/take-action</u> and make your voice heard in under 60 seconds!

NAAF advocates played key roles in introducing wig insurance coverage bills in California and New York. They also participated in early discussions of legislation introduced in more states in 2025. A similar wig bill was introduced in Illinois and signed into law.



"I am incredibly grateful for the opportunity to be part of the NAAF community and to lead such an impactful initiative as a Legislative Mentor. I'm excited to continue my journey with NAAF and help raise awareness for my alopecia friends!"

Kelsey M. Age 16

06 • 2024 NAAF ANNUAL REPORT

stronger TOGETHER

By Advancing Research & Education



Choice in treatment is driven by investment in alopecia areata research and integration of new therapies into patient care.

Those diagnosed with alopecia areata today have FDA-approved options to consider, an improvement over just a few years ago.

Research

NAAF Awarded \$270,000 in research grants in 2024. NAAF introduced the Early Career Award program to encourage interest and commitment and to bring new voices and ideas to the alopecia areata research field.

Research Grants continued to support scientists and clinicians exploring innovative approaches to understanding and treating the disease. Research dollars supported new investigations into the underlying biology of the disease and a potential new treatment delivery mechanism. By supporting new research, NAAF is paving the way for future advancements in understanding and managing the disease.

Grants Awarded in 2024

Early Career Awardee:

Ryan Hobbs, PhD, Assistant Professor, Department of Dermatology, Penn State Health; Project title: Uncovering autoimmune regulator function in alopecia areata

Early Career Awardee:

Leo Wang, MD, PhD, Assistant Professor, Department of Dermatology, Perelman School of Medicine, University of Pennsylvania; Project title: Hydrogel-based drug delivery in alopecia areata

Research Grant Awardee:

Monique Waldman, PhD, Postdoctoral Research Scientist, Department of Dermatology, Columbia University; Project title: Investigating the role of keratinocyte phagocytosis and antigen presentation in alopecia areata NAAF Student Internship Awards support students (undergraduate, graduate, medical), residents, or fellows interested in conducting research focused on alopecia areata.

NAAF's 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.

2024 Student Internship Awards

Vissy Elad, Northeast Ohio Medical University, Project title: Identifying methods to assess the psychological effects of alopecia areata in clinical settings; Mentor: Dr. Amy McMichael

Sujeeth Shanmugam, Wake Forest, Project title: Analyzing lab monitoring in alopecia areata patients under JAK inhibitors; Mentor: Dr. Amy McMichael

Deesha Desai, University of Pittsburgh School of Medicine, Project title: Evaluating outcomes and side effect profiles of Janus kinase inhibitors; Mentors: Dr. Jerry Shapiro & Dr. Kristen LoSicco

Ambika Nohria, NYU Grossman School of Medicine, Project title: Alopecia areata and vascular health; Mentors: Dr. Kristen LoSicco & Dr. Michale Garshick

Valia Leifer, Vagelos College of Physicians and Surgeons, Columbia University, Project title: Role of neurotransmittermediated t-cell dysfunction in the pathogenesis of alopecia areata; Mentor: Dr. Angela Christiano

2024 Travel Grants

World Congress for Hair Research, Dallas, Texas

Kailyn Valido, Yale School of Medicine, Abstract title: Combination oral minoxidil and baricitinib treatment of alopecia areata

Matthew Akiska, George Washington University School of Medicine and Health Sciences, Abstract title: Low-dose oral minoxidil initiation and monitoring (LOMI) for hair loss: A modified delphi consensus of experts

Sarah Choe, University of California Irvine, Abstract title: Characteristics of edema in pediatric and adult patients with alopecia areata on low-dose oral minoxidil

Mattea Johnson, University of Minnesota, Abstract title: Predicting psychosocial burden in adult alopecia areata patients: Demonstrating severity interaction effects and the limited utility of demographic and clinical history variables

John Frewen, Sinclair Dermatology, Abstract title: SALT score cards: Facilitating SALT score calculation in alopecia

Society of Investigative Dermatology, Dallas, Texas

Samuel Connell, University of Iowa, Abstract title: Exogenous IL-27 promotes immunosuppressive cells and prevents the development of alopecia areata in C3H/HeJ mice

Maddison Lensing, University of Iowa, Abstract title: Expansion of regulatory T cells restrains pathogenic CD8 T cells in a murine model of alopecia areata

Isaac Li-Chi Chen, Lahey Hospital and Medical Center, Abstract title: The pattern of Fas and Fas ligand expression in alopecia areata

Second Barcelona Hair Meeting

Emadodin Darchini-Maragheh, University of Melbourne, Abstract title: A hairy conundrum: An approach to hair loss disorders in general practice

Tools for Accessing Care and Treatment

Individuals living with alopecia areata, as well as dermatologists, are learning about the availability of approved treatments. In 2024, NAAF launched new website content for navigating insurance coverage for treatment and wigs.

NAAF's Doctor Finder continued to grow, expanding to include 139 healthcare providers by the end of 2024, a more than 75% increase in listings, covering 164 practice locations in 28 states, the District of Columbia, and Puerto Rico. Advanced practice providers were added to the Doctor Finder in 2024, in recognition of the care provided to the community by dermatology-trained nurse practitioners and physician assistants. The Doctor Finder continued to be one of the most popular pages on the NAAF website, with visits from more than 10,000 individuals to the Doctor Finder page and 36,000 page views. Special thanks to Eli Lilly & Co. and Sun Pharma for supporting this program.

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 biotech and pharmaceutical companies with the alopecia areata community to advance understanding of the patient-lived experience and accelerate discovery.

Diamond Partner

Gold Partners







Bronze Partners

Bristol Myers Squibb



Copper Partner



08 • 2024 NAAF ANNUAL REPORT • 09

stronger Together

By Building A Community & Making An Impact

Thanks to many thousands of walkers, donors, and generous sponsors, the 2024 Walk For Alopecia™ Presented by Pfizer raised over \$950,000; an incredible 54% increase over 2023.

NAAF's strong community can be justifiably proud, demonstrating that there are great needs that still must be addressed, and there is a powerful desire to do something about alopecia areata. Funds raised through the Walk For Alopecia help increase NAAF's mission impact to drive research, support the community and educate the public about alopecia areata.



To learn more about the Walk and how you can get involved as a team, donor, sponsor or volunteer, go to naaf.org/walk.



National Alopecia Areata Foundation



3,500+
REGISTERED

WALKERS

207

REGISTERED TEAMS

1.1M

MEDIA MENTIONS **15**

NEWSCASTS IN MAJOR MARKETS





On September 28, the last Saturday of Alopecia Areata Awareness Month, the alopecia areata community across the country set off on the 2nd Annual Walk For Alopecia to drive research for more treatments and a cure, increase support for individuals and families living with alopecia, to advocate, and to end stigma.

Excitement grew steadily from the nationwide announcement in May through the Walk kickoff at NAAF's Annual Conference in June and into the summer months. The momentum carried into August with a virtual kickoff event and a special live Instagram rally featuring Grammy-winning guitarist and songwriter Molly Tuttle. It all led up to walk day, when participants across the country came together sharing their stories on social media and showing up for one another. Every step taken inspired empowerment, connection, hope, joy, and greater awareness.

Thank you everyone who stepped up for this event!

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

"We're raising awareness which means less people will have to feel alone when they get diagnosed."

Brynn B.

"It makes me so warm and fuzzy inside just to see everyone here... and it gets better every year!"

Linda T.

"Awareness is the first step to progress, and we do that by uniting our communities."

Bailey W.

Thank You Sponsors

National Presenting Sponsor



Shining Bright National Sponsor



National Gold Sponsors

Eli Lilly & Co. RBC Capital Markets

National Silver Sponsors

AbbVie Sanofi

Local Top Sponsor
Optima Steel

Local Major Sponsors

Austin Institute For Clinical Research Nektar Therapeutics



In 2024, volunteer Shawn Borisoff engaged his employer, RBC Capital Markets, as a NAAF sponsor. As a result, NAAF received \$100,000 as a beneficiary of RBC's Charity Day For The Kids and through RBC's corporate philanthropy in support of the Walk For Alopecia and NAAF youth programming. On behalf of the alopecia areata community, including Shawn's own daughter, Brynn, we are deeply grateful for the generosity of and continued support from RBC Capital Markets.

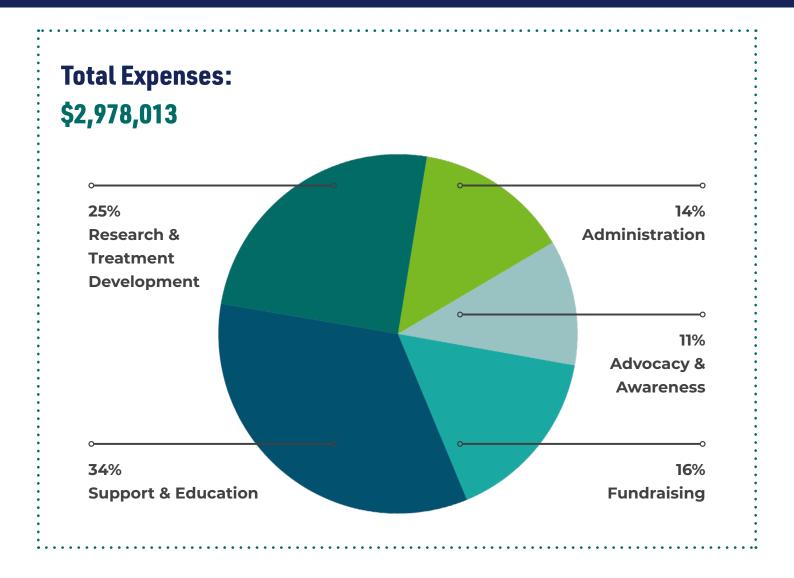


10 • 2024 NAAF ANNUAL REPORT

Financial Highlights

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





NAAF is a 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.

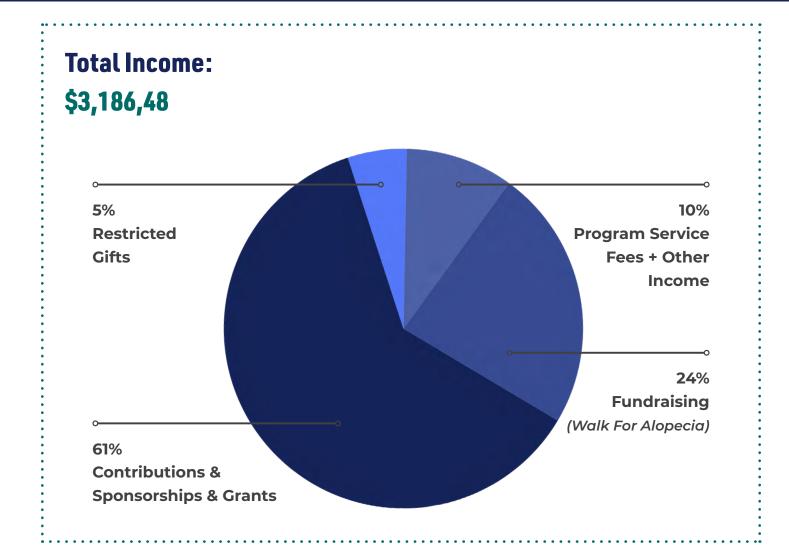
NAAF demonstrates excellence in governance, accountability, and transparency by earning the highest ratings on the following industry standards: the National Health Council Standards of Excellence; the Better Business Bureau – Wise Giving Alliance Standards for Charity; and Candid's Platinum rating (formerly GuideStar). In 2024, NAAF also received the highest (four-star) rating from Charity Navigator.











Ending Net Assets \$3,759,565

The complete audited financial statements are available at <u>naaf.org</u>.

12 • 2024 NAAF ANNUAL REPORT • 13



National Alopecia Areata Foundation™

For donations and payments:
PO Box 1270 | Suisun City, CA 94585

For all other correspondence and invoices: 1500 Grant Avenue | Suite 242 | Novato, CA 94945

415.851.8960 | <u>info@naaf.org</u>



naaf.org