

2021 *A Year of* **RESILIENCE**



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.

Looking back at 2021, the first word that springs to mind is resilience. Along with the alopecia areata community, NAAF persevered through the pandemic, facing major challenges, and yet emerging even stronger at the start of 2022.

2021 was a year of transition. NAAF's veteran Chief Administrative Officer, Jeanné Rappoport, kept NAAF on a forward-looking course through our CEO transition, which enabled the Foundation to thrive in 2021 even if most community activities, including the patient conference, had to remain virtual. We owe Jeanné, and the staff which supported her, a huge debt of gratitude for their commitment and care for NAAF and our community.

Later in 2021, NAAF ushered in a new era of staff leadership including new CEO and President, Nicole Friedland, who was recruited at the end of the year and officially started at the beginning of 2022. Nicole's three decades of experience includes over 20 years at the Juvenile Diabetes Research Foundation (JDRF), most recently as their Executive Director of the Northern California Chapter. Prior to JDRF, she served as Division President for National Kidney Foundation, Chief Development Officer at ReSurge International, and Director of Development at Seva Foundation. Lisa Anderson PhD, another veteran health nonprofit professional, came aboard as NAAF's new Research Director, bringing a strong grasp of clinical research that is already proving essential as we anticipate FDA-approved treatments in the very near future. Nicole and Lisa were joined by our new Support & Education Director, Judy Williams, who brings extensive patient support experience along with other community building skills.

Throughout 2021 NAAF unveiled our new Mission, Vision, and Values which incorporated significant input and engagement from our community. That same community continued to thrive by holding support group meetings, fundraisers and even, when safe, fundraisers and awareness events with local sports teams. US Congressional Representative Ayanna Pressley (D-MA), who herself has alopecia areata, showed her support for this community by introducing legislation that will make it easier for patients to afford cranial prosthetics. The darkest days of the pandemic receded as the alopecia areata community and NAAF began to bloom again.

This report chronicles significant progress in community outreach, achievements in research, and new levels of progress in legislative advocacy. This is the story of you and NAAF working together to come back stronger than ever. This is the story of resilience.

ANN HOLLINS
Chair, Board of Directors



As the National Alopecia Areata Foundation's new President and CEO, I am excited to join NAAF as it marks 40 years of service to the alopecia areata community and to build upon the exciting research advances that are taking place with autoimmune diseases at this pivotal time. I am inspired and motivated by the strength of the NAAF community and the profound challenges that individuals living with alopecia areata face. I look forward to partnering with all of you, along with the board and staff, to ensure that stronger support systems, new treatments, and more choices become available at an accelerated pace for our resilient community.

NICOLE FRIEDLAND
President and CEO

My group has been an invaluable source of support, friendships, and information-sharing.

I have often found that no one really knows about an experience unless they walk in the same shoes. This is so true with alopecia, but my support group friends truly understand what it's like to navigate life with hair loss. It can be an emotional and psychological trauma that dominates and significantly alters one's life but having a network of others with alopecia can be a vital resource for all of us to find comfort and share important information so that we can move forward. We all have the chance to benefit from each other, no matter what stage we are in. Newcomers are often encouraged to see others who are thriving despite their hair loss, and many are eager for helpful information, whether it's treatment or medication options, resources for wigs and their care, various cosmetic solutions, or just the challenges of living with alopecia. Having alopecia is a journey with many ups and downs, but I'm grateful for a circle of friends who truly understand living with it, to provide hope and help lift each other up.



CAROL HOPPER
Support Group Leader

SUPPORT

“... MY SUPPORT GROUP FRIENDS TRULY UNDERSTAND WHAT IT'S LIKE TO NAVIGATE LIFE WITH HAIR LOSS.”

SUPPORT

HOW WE CREATED COMMUNITY AND EMPOWERED PEOPLE LIVING WITH ALOPECIA AREATA IN 2021



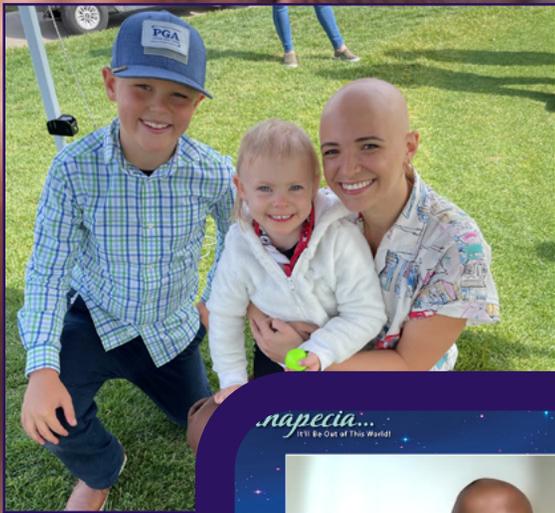
169 PEOPLE attend Lunapecia, NAAF's second Conference held entirely online. Videos from the Conference attract **358 VIEWS**.



353 BRAVE BARBIE DOLLS are shipped to alopecia areata families around the world.



1040 INQUIRIES (phone and email) are answered, a **5% INCREASE** over the previous year.



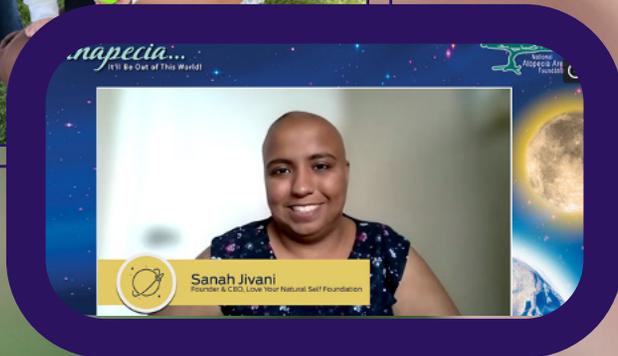
638 PEOPLE participate and are helped by **96 NAAF VIRTUAL SUPPORT GROUP MEETINGS** around the country.



223 MENTORS & 244 MENTEES participate in the Youth Mentor program, resulting in **115 MATCHES**, reflecting a **5% GROWTH**.



3,157 VIEWS of the "Let's Talk" webinar series, created and hosted by Drs. Angela Rodgers and Renee Thomason, on NAAF's YouTube channel.



One of the most rewarding activities for me is working with NAAF as a Legislative Mentor. Back in 2019, when I first became acquainted with NAAF through their support group meetings, I never imagined that I would have the opportunity to work with the foundation. I have always admired their efforts to unite the alopecia community through support group meetings, sports events, and their annual Hill Day in Washington, D.C. Now alongside other Legislative Mentors throughout the United States, I am working to make a lasting impact for the alopecia community.

Above all things, the experience I've gained as a Legislative Mentor empowers me as an advocate for change. In September of 2021, I had the privilege of meeting my role-model, Congresswoman Ayanna Pressley. The other mentors and Gary Sherwood, NAAF's Communications Director, have equipped me with the necessary tools to engage in effective conversations with my district's congressman. Everyone works to make a difference. I have also furthered the efforts of the Legislative Mentors by creating the Alopecia Justice League (AJL) with other patient advocates in New York City. **The Instagram handle is @alopeciajusticeleague. Our achievements make my work as a Legislative Mentor truly rewarding.**

ALISON LEE, Legislative Mentor



ADVOCACY & AWARENESS

“... THE EXPERIENCE I'VE GAINED AS A LEGISLATIVE MENTOR EMPOWERS ME AS AN ADVOCATE FOR CHANGE.”

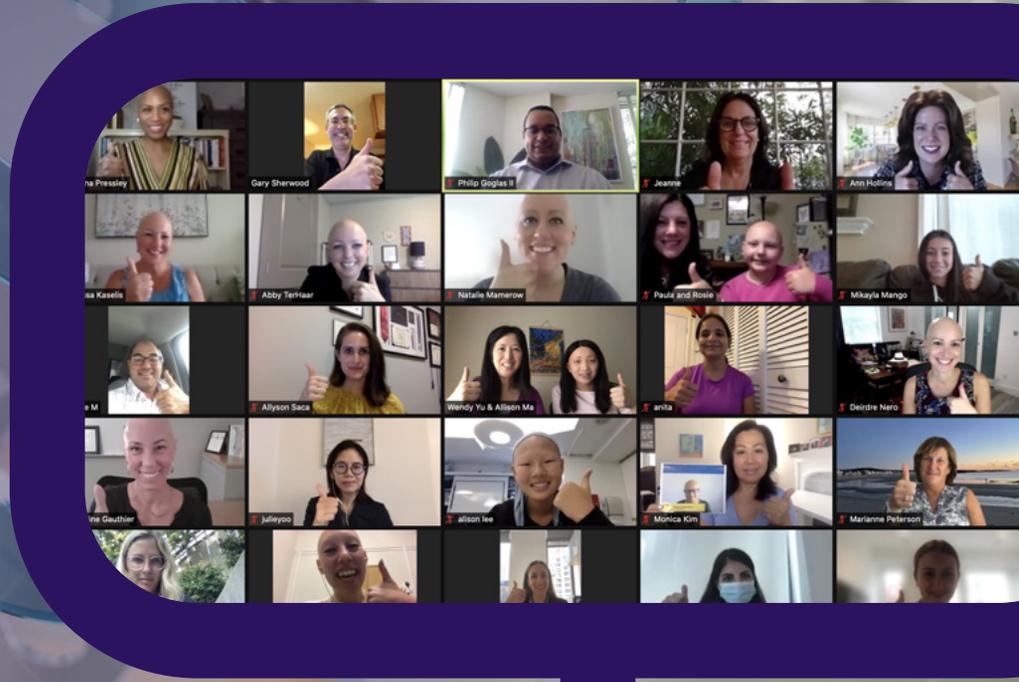
AWARENESS

WE RAISED PUBLIC AWARENESS AND ENHANCED HOW ALOPECIA AREATA IS PERCEIVED AND APPROACHED



REPRESENTATIVE AYANNA PRESSLEY (D-MA)

holds a Zoom meeting with the NAAF Advocacy Committee to discuss legislative priorities for the alopecia areata community (of which she is a member!). Representative Pressley also meets in person with the Boston Support Group led by Chrissa Kaselis.



H.R. 5430 IS INTRODUCED

This important legislation, led by Representatives Jim McGovern and Ayanna Pressley (both D-MA), would reclassify wigs as durable medical equipment eligible for Medicare assistance.



\$1.25 BILLION INCREASE IN FUNDING

is approved by Congress for medical research programs at the National Institutes of Health. Of that, \$ 655 million, a \$21 million increase over the previous fiscal year, is slated for the National Institute of Arthritis and Musculoskeletal and Skin Diseases which has an alopecia areata research portfolio.

ADVOCACY

AWARENESS



323 LEGISLATIVE LIAISONS (14 coming aboard in 2021) **AND 9 LEGISLATIVE MENTORS** (young people interested in the legislative process but not yet old enough to become a Legislative Liaison) participate in **70 VIRTUAL LEGISLATIVE MEETINGS**.

Veteran Legislative Liaisons also participate in the American Academy of Dermatology's virtual Hill Day.



4 TEAM UP AWARENESS GAMES

organized as these events return on a limited basis, and community volunteers follow local safety guidelines.



495 MILLION IMPRESSIONS – an 11% increase over 2020 - created by **45 MEDIA MENTIONS** of alopecia areata and/or NAAF in such diverse outlets as *ABC News, Allure, the BBC, Billboard, Black Enterprise, CBS News, CNN, Dermatology Times, Fox News, Good Morning America, NBC News, The New York Daily News, The Philadelphia Tribune, The Source, Us Magazine* and multiple podcasts including *Alopecia Life, Newstalk, Women of Significance* and the *Talk Hair Loss* podcast out of the UK.



25 VOLUNTEER-LED EVENTS spread awareness and raise \$167,999.

ADVOCACY

Alopecia areata research has expanded within the last year to include new studies investigating therapeutics, genetic or immune factors, and psychosocial impacts of alopecia areata. Studies investigating the therapeutic use of new topical and systemic agents, such as janus kinase inhibitors, and light-based therapies, such as low-level laser therapy, have developed. This year, studies assessing immunomodulator treatment options not only for alopecia areata, but also for alopecia areata with concomitant atopic dermatitis, have been published. Investigation into interleukin and immune cell involvement in this disease have continued to evolve. Notably, the psychosocial aspects of living with alopecia areata are now almost routinely part of alopecia areata research studies. COVID-19 and alopecia research has also developed with the creation and continuation of alopecia registries to better understand the impact of COVID-19 on hair loss, as well as the impact of alopecia areata therapeutics on COVID-19 infection.

Within the last year, NAAF has continued to expand its online support groups and educational opportunities. Remarkably, this included a fully virtual annual conference in June. The conference facilitated discussions, sessions, and workshops connecting patients, researchers, clinicians, and physicians. It further provided updates on new alopecia areata therapies by experts in the field and reminders of mentorship and support opportunities available within the alopecia areata community. Most importantly, it allowed for a return to a sense of normalcy and connection within NAAF, a typically tight-knit community. This was needed after COVID-19 prevented such in-person experiences. Excitingly, the conference this year is expected to be held in person.

Only a few of the expansive research topics investigated this past year have been mentioned, and these are only the tip of the iceberg in what is to come in alopecia areata research. The resilience of the alopecia areata community has shone within the last year. With the support of NAAF, research, education, and sense of community have persisted and thrived despite the hardships COVID-19 has caused. This coming year is one of promise, hope, and further innovation.



MARIA HORDINSKY, MD, FAAD
Professor and Chair of the Department of Dermatology
at the University of Minnesota



BRIANA PAIEWONSKY
Predoctoral Research Fellow Department of Dermatology
at the University of Minnesota

TREATMENT DEVELOPMENT PROGRAM

TREATMENT DEVELOPMENT PROGRAM

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



\$161,180 in funding through current grant awards support 7 basic, translational, and clinical research projects in alopecia areata.



3 dermatological journals (*JAMA Dermatology*, *Dermatologic Therapy*, and *Clinical and Experimental Dermatology*) published articles co-authored by NAAF.



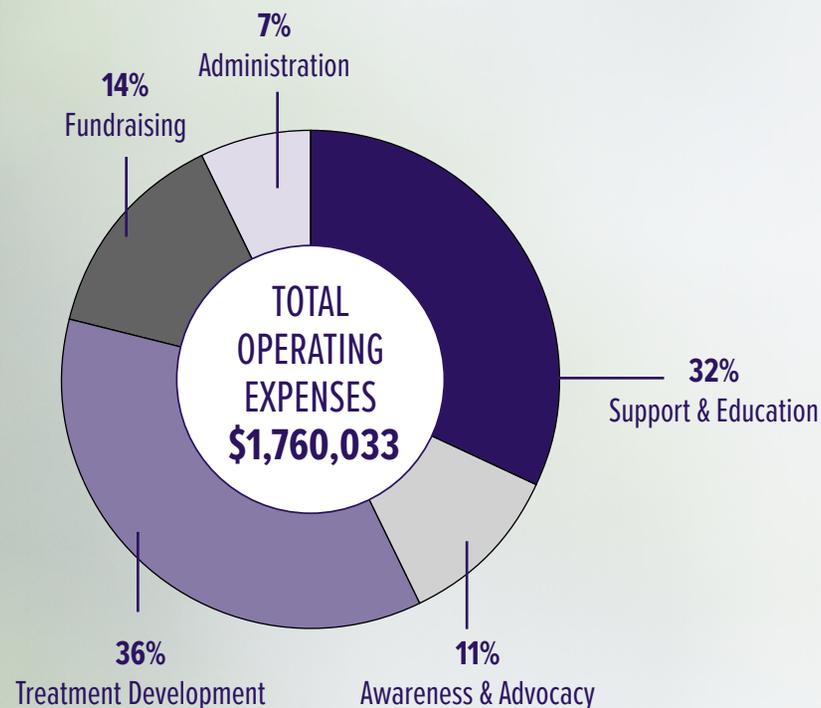
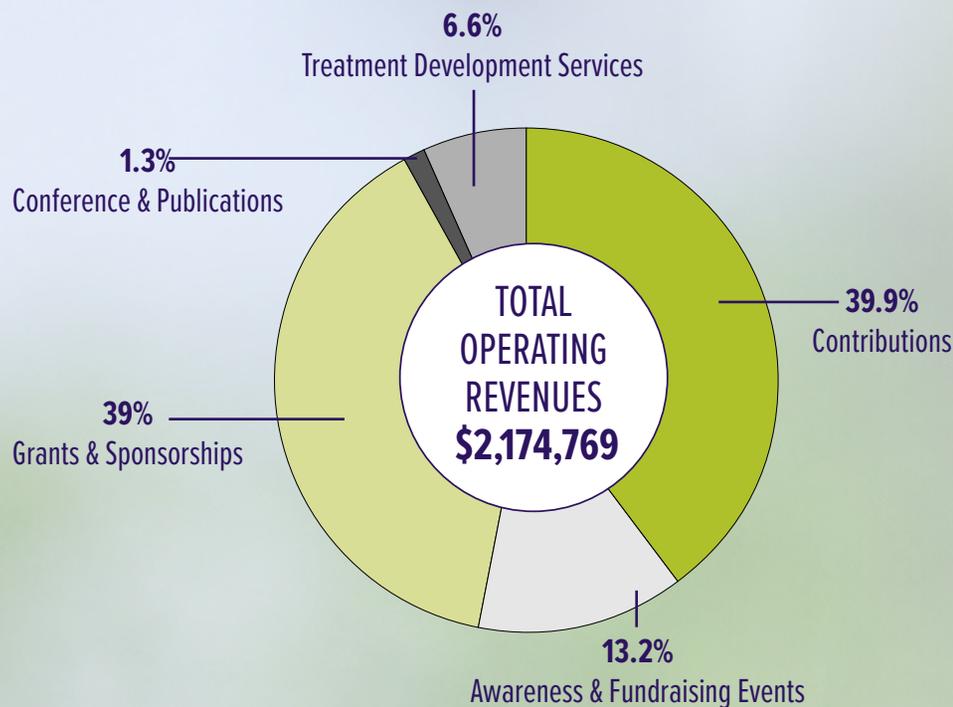
8 community members joined an industry-sponsored roundtable to share their perspectives on living with the disease.



5 clinical studies and 4 academic survey studies gain recruits via NAAF website, emails, and social media channels.

FINANCIAL HIGHLIGHTS

THERE IS STRENGTH IN NUMBERS, ESPECIALLY THOSE DEMONSTRATING OUR COMMITMENT TO SUPPORT, AWARENESS AND RESEARCH.



ENDING NET ASSETS
\$2,234,735

The complete audited financial statements are available on the website at naaf.org or by mail from the San Rafael office.

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Donors to NAAF provide critical financial support and represent a growing community that have allowed us to expand our support and education programs and drive research to find an acceptable treatment. Donors also strengthen us by introducing NAAF to their communities. We thank you for your support.

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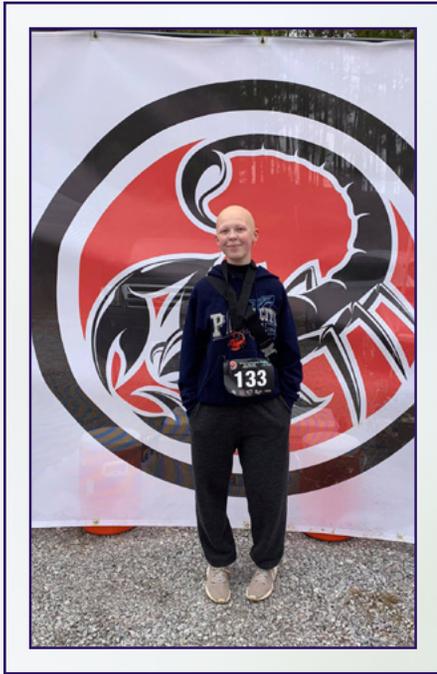
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