

National Alopecia Areata Foundation

# A YEAR OF HEROES

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2018 Annual Report



If you or someone close to you has alopecia areata and you've acted to help the community in some way, you too are a superhero.

**Dory Kranz**  
President and Chief Executive Officer



**Bob Flint**  
Chair, Board of Directors

## 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.

In 2018, the movie screens were full of superheroes and so was our community! If you wanted to see *Black Panther*, or *Aquaman*, chances are you had to wait in line. Yet we at the National Alopecia Areata Foundation saw superheroes every day without ever having to buy a ticket.

Kate Ekman and Anamarie Tan were a classic dynamic duo as they met with legislators in Southern California and on Capitol Hill, and convinced congressional representatives to support NAAF's efforts by co-sponsoring H.R. 2925, legislation that would help the entire American alopecia areata community by providing coverage for cranial prosthetics as durable medical equipment under the Medicare program. These two powerhouse young women are emblematic of the many dedicated community members who make up the Legislative Liaisons, a program that grows more effective every year.

Andrea Konopka displayed her superpowers of understanding and personalized support as she mentored Amelie Olofsson on how to better cope and grow stronger from her own alopecia areata experience. And other Youth Mentors did the same! 2018 was the first full year of our Youth Mentor program, and its growth has been phenomenal as more and more children and teens with alopecia areata—and their parents—benefit from the experiences of other young people with the same disease.

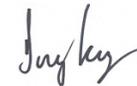
Arash Mostaghimi, ace alopecia areata investigator, summoned the power of the voice of the patient to better illuminate the burden of this disease and demonstrate how vital patient input can help develop better treatment outcomes and even insurance approval. Arash also harnessed the dynamism of scientific discovery to create a more accurate and up-to-date prevalence study, helping researchers better understand not just how many people are affected by alopecia areata but the severity of the condition.

And like a certain animated superhero family, the Kaye family united to form an *incredible* team of action and support with their sponsorship of the Youth Mentor program. Additionally, Ernie Kaye courageously brought alopecia areata awareness to the fore with his poetry, photography and bold presentation to his school.

These are the community member superheroes we spotlight in the pages of this annual report, but there are so many more out there. If you or someone close to you has alopecia areata and you've acted to help the community in some way, you too are a superhero. In the tradition of Peter "Spiderman" Parker or Diana "Wonder Woman" Prince, your own school or workplace may not know all the good you've done . . . but we do. And so does the alopecia areata community. On behalf of them, we thank you and pledge to honor your heroism by redoubling our efforts to bring about a world without suffering from alopecia areata—a world built by heroes like you.



**Bob Flint**  
Chair, Board of Directors



**Dory Kranz**  
President and  
Chief Executive Officer





**When I was diagnosed with alopecia totalis at a young age,** I didn't know anyone with a similar experience. I grew up in a supportive environment, but I wish I had had a mentor who could relate to my struggles and with whom I could share personal thoughts and ask questions: How do I tell my friends? What treatments are available?

I am thankful to the National Alopecia Areata Foundation for building the Youth Mentor program and providing children and teenagers a support network. I am proud to be a part of this community and serve as a Youth Mentor.

When I was matched to my mentee, Amelie, I was overwhelmed with honor and excitement. Amelie is a five-year-old girl who was recently diagnosed with alopecia universalis. During our first interaction, an introductory phone call, I spoke mostly to her parents and shared my story while answering any initial questions. We then arranged to meet in-person. I arrived at the restaurant and saw a beautiful, yet rather shy ballerina with no head covering. I walked in, and after introducing myself, I proceeded to take off my winter hat along with my bandana, a staple item in my wardrobe. I wanted Amelie to see that my head was also totally hairless. Each time I see Amelie, I take off my bandana and each time she opens up a little more. Due to her young age, Amelie may not understand treatments or social perceptions, but she understands that she is not alone. For that reason, and many more, I feel blessed to be Amelie's mentor; this experience has been very rewarding. Amelie inspires me to be a better advocate for the alopecia community and I have even been embracing "the bald look."

As someone who has 18 (and counting) years of experience, there are highs and lows to this autoimmune disorder. I will continue mentoring Amelie throughout her alopecia journey, or for as long as she needs a mentor or a friend. As Amelie matures, she will have more questions and I am ready to answer them. To anyone coping with alopecia, please reach out to me or someone in our supportive community we are willing, able, and anxious to help!

**ANDREA KONOPKA, Youth Mentor**



## SUPPORT

CREATING COMMUNITY AND EMPOWERING PEOPLE  
LIVING WITH ALOPECIA AREATA

**1,447**

people participate in and are helped by **133** NAAF support group meetings around the country.

**6,967**

inquiries are answered, **630** Ella dolls are shipped, and **133** people are assisted with wig purchases by grants from NAAF.

**148**

Mentors and **107** Mentees participate in NAAF's Youth Mentor program, resulting in **54** matches.

**2,646**

new posts created by **931** members of the new alopecia areata community of the online SmartPatients organization.

**691**

people attend the annual NAAF Conference. **102** attendees (including **40** children and teens) receive scholarships helping pay for a portion of the cost.





**Since 2012 we have better** informed and built relationships with our elected officials through the Legislative Liaison program. These community members meet with and educate their congressional representatives and senators both at home and on Capitol Hill. Throughout 2018 the Legislative Liaisons secured the support of 23 congressmen and women who agreed to cosponsor the bill H.R. 2925, which would have reclassified cranial

prosthetics as durable medical equipment eligible for Medicare (the bill will be reintroduced with a new number in 2019). Among our most energetic legislative champions are the two-woman team of Kate Ekman (pictured left) and Anamarie Tan (pictured right).

Meeting Anamarie was really special for me because she was the first woman with alopecia I'd met who lives her life bald. She told me her unique story and I admired her resilience and style. Plus, teaming up worked! We were selected to go to Washington DC for Hill Day together, and we set up NAAF fundraisers to help the organization with the cost of the trip. I realized I'd never had a tangible way for my friends and family to support me with my disease. My work with NAAF and the inspiration I felt from seeing Anamarie thrive has helped me "come out." In DC we advocated with other Legislative Liaisons, which was a really wonderful experience of camaraderie. And it led us to success in securing Rep. Ted Lieu's co-sponsorship of H.R. 2925!

**KATE EKMAN, Legislative Liaison**

Being involved with the Legislative Liaison program was a truly life-changing experience. I found my passion for advocacy and awareness, and connected with my first real-life alopecia friend, Kate! I learned how powerful my voice can be when having open conversations about my appearance as a bald woman. I also learned the importance of raising awareness about alopecia. Shortly after, I was invited by NAAF to go to Washington, DC, to advocate at Capitol Hill! Having our Hill Day to look forward to, I was inspired to create a team fundraiser with family and friends during Alopecia Awareness Month, and we raised over \$5,000! Seeing this accomplishment and securing Rep. Lieu's co-sponsorship has encouraged me to continue using my voice to raise awareness and create change.

**ANAMARIE TAN, Legislative Liaison**

# AWARENESS & ADVOCACY

## RAISING PUBLIC AWARENESS AND ENHANCING HOW ALOPECIA AREATA IS PERCEIVED AND APPROACHED

**\$2 billion**

increase in funding approved by Congress for medical research programs at the National Institutes of Health which is the amount for which we were advocating. Of that, **\$605 million**, an **\$18.4 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 portfolio.

**79**

volunteer-led events spread awareness and raise **\$264,000**.

**6**

senate offices meet with Gary Sherwood and Legislative Liaisons Allyson Saca and Ebony Jean during a separate mini-Hill Day in an effort to find an author for a senate companion bill to H.R. 2925.

**244**

Legislative Liaisons (**40** coming aboard in 2019) participate in **72** legislative meetings both in district offices at home and in Washington, DC, including our 5th annual Day on Capitol Hill. This is our largest Hill Day to date outside of our DC NAAF conferences, and we plan to grow it further.

**440 million**

impressions created by **49** media mentions of alopecia areata and/or NAAF in such diverse outlets as USA Today, Sports Illustrated, CNN, the BBC, and many others help spread awareness.

**17,391**

viewers see **10** community videos during Awareness Month What's Your Super Power? campaign which raises **\$110,000**.





## NAAF WORKS WITH SUPER HEROES IN RESEARCH TO FIND A TREATMENT

**2018 marked another exciting year of progress** for the alopecia areata community. As our partnerships between patients, scientists, and industry mature we are closer every day to the first of hopefully many safe, effective, and FDA-approved therapies for alopecia areata. While developing new medications is tremendously exciting, it is critical that we simultaneously continue to build a foundation of research that translates the impact that alopecia areata has on patients from anecdotes and stories to rigorous data that can be used to convince government agencies and insurers to approve and pay for these medications.

Fortunately, with the support of NAAF, industry partners and the alopecia community itself, we are making progress on this front as well. In the past year, publications on the financial burden of alopecia areata on patients, the impact of alopecia areata on sexual quality of life, and the utilization of mental health resources and complementary therapies by patients with alopecia areata have started to quantify the impact of this disease on patients. These studies, in combination with ongoing advocacy efforts by the NAAF community are beginning to justify to the Food and Drug Administration and insurers the critical needs of patients with alopecia areata.

Ultimately, the benefits of new and effective medications for alopecia areata can only be realized when these drugs are paid for by insurance and affordable for patients from all socioeconomic backgrounds. I am thankful to NAAF and its members for their ongoing efforts in this area, and with continued and systematic effort I am excited for a future where the significance and value of treatments for alopecia areata are no longer up for debate, but an accepted standard in healthcare.



**ARASH MOSTAGHIMI, MD, MPA, MPH**  
ASSISTANT PROFESSOR  
DEPARTMENT OF DERMATOLOGY  
BRIGHAM & WOMEN'S HOSPITAL

## TREATMENT DEVELOPMENT PROGRAM

SUPPORTING RESEARCH TO FIND A CURE OR ACCEPTABLE TREATMENT

**113**

**researchers and interested parties** representing **35** academic institutions and research centers across the globe, **34** biopharmaceutical industry representatives, **10** representatives from government other organizations, and **26** early career investigators participate in 2-day Research Summit to set the strategic direction for our Treatment Development Program.

**\$556,283**

in research funding, through current grant awards and future commitments support **7** basic, translational, and clinical research projects in alopecia areata

**23**

Health and Research Ambassadors participate in roundtables and focus groups to inform industry of patient preferences.

**18**

clinical studies gain recruits via NAAF website, emails and social media channels.

**2**

publications elevate the significant burdens and impacts of alopecia areata.

**7**

travel grants totaling **\$8,400** support young investigators.

- NAAF and Collaborative consortium develop draft patient-reported outcomes instrument for alopecia areata and an initial briefing report is submitted to the Food and Drug Administration.
- FDA releases its Voice of the Patient Report highlighting the significant psychosocial impacts of living with alopecia areata to help drive the benefit risk assessment of potential new treatments.
- NAAF coordinates publication of "Alopecia Areata is a Medical Disease" article to help elevate awareness of the tremendous physical, emotional, and social toll of alopecia areata on affected individuals and move the public agenda forward.
- NAAF transfers administration and ownership of Alopecia Areata Registry data and associated samples for the next phase of growth and accessibility, ensuring its longevity.

Tortoise and The Hair  
Alopecia 5K



Tortoise and The Hair  
Alopecia 5K





## COMMUNITY SPOTLIGHT

I was diagnosed with alopecia areata during my freshman year of high school. My sudden hair loss was difficult to cope with and resulted in my wearing hats everywhere, covering as much of my face as possible. Embarrassed by the onset of my alopecia, I avoided telling my friends for weeks, and was often laughed at for my “new look.” After months of feeling depressed, it was time for me to take action. I was introduced to NAAF, and we have since formed a powerful relationship. I am grateful for all that NAAF has helped me accomplish through two years of support. Last year, I delivered a speech at my former middle school on “being different.” It marked the first time that I shared my story to a group of people, and NAAF was there to support me. For my school photography project, I created a book dedicated to alopecians, taking portraits of wonderful people willing to be a part of my project thanks to introductions made by NAAF. With the help of NAAF, my family and I have launched a fundraiser to help support the Youth Mentor Program. So far, we have raised 75 percent of our initial goal of **\$250,000!**

My character has grown immensely over the past two years. Learning to cope with a disease that makes me look different has made me a stronger, more compassionate person. I am so fortunate to have NAAF in my life.

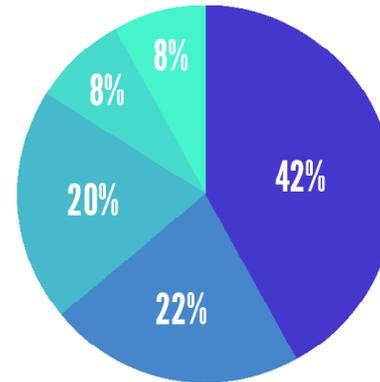


**ERNIE KAYE,**  
NAAF COMMUNITY MEMBER

## 2018 FINANCIAL HIGHLIGHTS

### 2018 OPERATING REVENUES\*

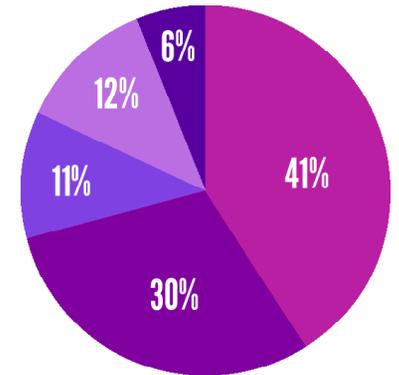
\$2,110,715



- Contributions - 42%
- Grants & Sponsorships - 22%
- Awareness & Fundraising Events - 20%
- Treatment Development Services - 8%
- Conference and Publications - 8%

### 2018 OPERATING EXPENSES S/B

\$2,563,689



- Support & Education - 41%
- Treatment Development - 30%
- Awareness & Advocacy - 11%
- Fundraising - 12%
- Administration - 6%

\*Note: Total operating revenue excludes a net investment return of (\$87,910)

ENDING NET ASSETS  
**\$2,650,454**

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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\$50,000-\$150,000

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\$25,000-\$49,999

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#### Industry Sponsors

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We are grateful for the collective generosity of our supporters.

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