



National Alopecia Areata Foundation

# A SYMPHONY OF VOICES

2017 Annual Report




“NEVER SACRIFICE YOUR INDIVIDUALITY AND NEVER REGRET THE DECISION TO BE YOURSELF. LOVE THE BODY YOU HAVE BEEN BLESSED WITH AND THE STORY THAT IT TELLS. WITH THAT TRUTH YOU CAN MAKE ANY OBSTACLE SOLVABLE. BE YOU – BEAUTIFUL.”

NELL SANDERS, *BEAUTIFUL*

Performed at the 2017 NAAF International Conference



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.

**We could not have done this solo.  
It was a symphony—a symphony of voices.**

In 2017, we invited the world to HearUs. Our story was shared often and in many ways, empowering the storytellers and the listeners. Our [Concert of Voices](#) in Nashville, featuring performances from Dani Dease, Becky Hibbs, Samuel (the artist formerly known as Sammy C), Nell Sanders, Miranda Soong, and hosted by Georgia Van Cuylenburg—all of whom live with alopecia areata—told the story in rap, slam poetry, standup comedy, and foot-stompin’ country & western songs. Our [patient conference in Miami](#) featured bluegrass great Molly Tuttle, who also has alopecia areata, inspiring attendees with her music.

The symphony was heard in Washington, DC as Legislative Liaisons related our stories on Capitol Hill. It was heard in empowering gatherings where Health and Research Ambassadors shared vital knowledge about the value of the patient voice in research in their local communities. And, it was heard by young people from their Youth Mentors.

The symphony was not only heard – it was read in the Journal of Investigative Dermatology Symposium Proceedings where findings from our latest alopecia areata research summit entitled Building and Crossing the Translational Bridge were published.

And in a crescendo the symphony at long last reached the ears—and opened the hearts and minds—of people at the [Food and Drug Administration \(FDA\)](#). When 170 of us arrived at the Bethesda campus of the FDA—and another 200 joined the meeting virtually—the alopecia areata community was represented by empowered, impassioned people from a broad range of ages, backgrounds, severity and duration of disease. Over the course of four meaning-rich and emotionally impactful hours, voices—empowered by years of teaching and learning, giving and receiving, crying and laughing—raised up as a resonant chorus and created a sweeping narrative arc calling forth the pain of the past and present while pointing us toward the triumph of the future.

For individuals and families, young and old, newly diagnosed or veterans of this disease, 2017 was the year to join this symphony of voices. It was extraordinary in that our community members were not merely the players. Each was composer and conductor as well, crafting the story, guiding the symphony to sing us into a world where no one suffers from alopecia areata.

BOB FLINT  
CHAIR, BOARD OF DIRECTORS

DORY KRANZ  
PRESIDENT AND  
CHIEF EXECUTIVE OFFICER

NASHVILLE



## NAAF's Youth Mentor Program Provides Guidance and Support to Young People...by Young People!

In October 2017, NAAF formally launched the [Youth Mentor Program](#), connecting children living with alopecia areata and their parents to young adult mentors, to create meaningful bonds while providing support and guidance.

Our mentors are people with alopecia areata between the ages of 17 and 30 who wish to provide one-on-one support. NAAF mentors help children and their guardians by sharing their own journey navigating different aspects of life with alopecia areata. Their time, dedication and experiences helps bring a sense of "normalcy" to kids and their families at a time when it is most needed.

Based on initial feedback about the program's positive impact, we seek to match every child and/or guardian with a dedicated mentor by 2020. This program is a welcome addition to the support pillar of our mission statement and received positively by our community.

*I would love my daughter to meet a young woman who can show her that she will get through it and that it's ok to be upset, and how to channel those feelings more productively.*

RENEE, MOTHER TO A CHILD WITH ALOPECIA AREATA

*I volunteer as a Youth Mentor with NAAF because I know how alone and isolated having alopecia can make you feel. When I was growing up, I never met anyone who had alopecia. Now is my time to mentor, and hopefully prevent someone from feeling that way.*

JOHN, YOUTH MENTOR



## Support

Creating community and empowering people living with alopecia areata

IN THE COMMUNITY	FROM THE OFFICE	AT THE CONFERENCE	ONLINE
58 VOLUNTEER-LED SUPPORT GROUPS HELD 122 MEETINGS	6,950 INQUIRIES ANSWERED	564 ATTENDEES	WEBSITE 481,816 TOTAL VISITS
59 TELEPHONE SUPPORT CONTACTS	848 ELLA DOLLS DISTRIBUTED	87 SCHOLARSHIP RECIPIENTS INCLUDING 26 CHILDREN AND TEENS	381,762 FIRST-TIME VISITORS
SMARTPATIENTS 648 TOTAL CONFIRMED MEMBERS	146 ASCOT FUND GRANTS AWARDED		
1,100 CONVERSATIONS			
YOUTH MENTOR PROGRAM 51 MENTORS READY TO SERVE			
6 CHILDREN PAIRED WITH A MENTOR			



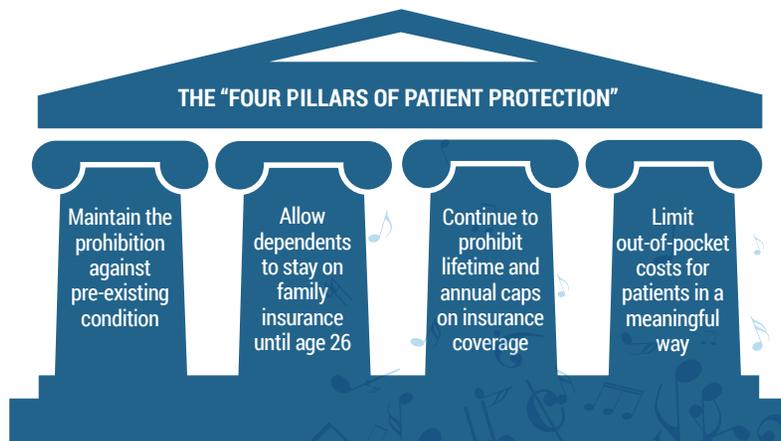
NAAF extends a special thanks to **Nell Sanders**, **Rafi Wasserman** and **Angelina Quezada** for helping to envision and design the Youth Mentor Program, and to **Maureen Smith** for championing the program within NAAF.

## NAAF's Legislative Liaisons Defend Your Rights as a Patient

As threats to repeal and replace the Affordable Care Act in 2017 imperiled the "Four Pillars of Patient Protection" that benefited the alopecia areata community, the Legislative Liaisons defended these protections both in meetings with their legislators and by responding to five Action Alerts advising lawmakers to vote against any measure that would endanger these protections. The Legislative Liaisons also played a dominant role in helping secure our Patient-Focused Drug Development meeting with the [FDA Patient Focused Drug Development meeting](#) with the FDA [make live link to VoP report], and many were in attendance, including Sarah Seward of Hampton, VA, who offers these thoughts:

This past year was a whirlwind. I learned just how important the "Four Pillars of Patient Protection" were, and how we will never surrender them. The Legislative Liaison program gave me a voice that I never knew that I had. When I joined this unstoppable group of people four years ago, I had no idea I was going to witness so many awe-inspiring moments. I had no idea these people would become my safe place, providing the clarity that everything does indeed happen for a reason.

In 2017, we had the opportunity to meet with the FDA. This was something that we had been advocating for from the program's beginning. To witness and be a part of this meeting was something of a dream come true. For all of us to be able to come together and express ourselves in the rawest form is truly a memory I will never forget. We are in this together, and we will never stop the fight, this is just beginning.



### Awareness & Advocacy

Raising public awareness and enhancing how alopecia areata is perceived and approached

**204**  
LEGISLATIVE  
LIAISONS HELD  
**63** MEETINGS  
WITH  
LEGISLATORS

**49**  
VOLUNTEER-LED  
**EVENTS** RAISED  
AWARENESS AND  
RESOURCES

**370**  
COMMUNITY  
MEMBERS  
PARTICIPATED IN  
FDA'S PATIENT  
FOCUSED DRUG  
DEVELOPMENT  
INITIATIVE  
MEETING ON  
ALOPECIA  
AREATA

**33**  
MENTIONS IN  
NEWS AND  
PUBLICITY  
OUTLETS  
AROUND  
THE WORLD  
(INCLUDING ABC  
NEWS, CNN,  
**THE TODAY  
SHOW**) AND  
THE HIT SERIES  
**THIS IS US**  
CREATING **365**  
**MILLION** MEDIA  
IMPRESSIONS





## NAAF Works to Make Sure the FDA Hears – and Listens – to Us

The future is bright for the alopecia areata community. Beginning with a single report of reversal of alopecia universalis with tofacitinib almost four years ago, there is now compelling evidence of the efficacy of Janus kinase (JAK) inhibitors for this condition, and several pharmaceutical industry-sponsored clinical trials are underway. We are on the path toward FDA approval of effective treatments for alopecia areata!



While we have come so far in a short time, important questions remain, not the least of which is: what clinically meaningful endpoints should be used to measure outcomes in clinical trials? In other words, how much hair does someone with alopecia areata need to regrow in order to consider the treatment a success? What about eyebrow and eyelash hair? And hair loss is just one symptom of alopecia areata. What about the psychosocial impact of this condition? Does successful reversal of hair loss improve quality of life? Without answers to these questions, the FDA will struggle to evaluate the data emerging from clinical trials.

The FDA's recent [Patient-Focused Drug Development Public Meeting](#) for Alopecia Areata provided an opportunity for the community to help the FDA begin to understand what life is like for people with alopecia areata and what matters to them. Attendance at the meeting was spectacular. Patients spoke of their individual experiences as well as common struggles. Some bravely shared stories of tragedies that had befallen them due to alopecia areata, and others told of triumphs such as the reversal of alopecia areata with currently available medicines. Together, the community spoke, making a compelling case for alopecia areata and its treatment and laying the foundation for understanding clinical outcome measures.

The discovery of an effective treatment for alopecia areata almost four years ago was built on almost [30 years of research](#). I am hopeful that the road from where we are now to the goal—not one but many FDA-approved treatments for alopecia areata—will be relatively straight and short. The Patient-Focused Drug Development Public Meeting for Alopecia Areata was a critically important stop on the path, and I thank NAAF and its members for getting us there. We will continue to move forward and enjoy more successes.

BRETT KING, MD, PHD  
ASSOCIATE PROFESSOR OF DERMATOLOGY  
YALE SCHOOL OF MEDICINE

## Our Treatment Development Program

Supporting research to find a cure or acceptable treatment

**17** HEALTH AND RESEARCH AMBASSADORS MOBILIZE **420** PEOPLE AROUND ALOPECIA AREATA RESEARCH THROUGH COMMUNITY TRAINING SESSIONS ON PATIENT-CENTERED OUTCOMES RESEARCH & COMPARATIVE EFFECTIVENESS RESEARCH ACROSS THE COUNTRY

**333** CONFERENCE ATTENDEES PARTICIPATE IN THE FIRST BIO-PHARMA INDUSTRY PANEL TO DIRECT TREATMENT EFFORTS TOWARD THE MOST DESIRED END RESULTS

**\$479,423** IN GRANT AWARDS SUPPORT 6 BASIC, TRANSLATIONAL, AND CLINICAL RESEARCH PROJECTS

**2** FDA CRITICAL PATH INNOVATION MEETINGS ARE CONVENED WITH MORE THAN 50 INDUSTRY AND GOVERNMENT REPRESENTATIVES TO IMPROVE EFFICIENCY AND SUCCESS IN ALOPECIA AREATA DRUG DEVELOPMENT AND BENEFIT-RISK REVIEW OF NEW TREATMENT OPTIONS

**4** TRAVEL GRANTS TOTALING **\$3,525** SUPPORT YOUNG INVESTIGATORS

**15** REPORTS FROM THE 2016 ALOPECIA AREATA RESEARCH SUMMIT ARE PUBLISHED IN THE JOURNAL OF INVESTIGATIVE DERMATOLOGY SYMPOSIUM PROCEEDINGS REACHING **6,855** SUBSCRIBERS

## Our Accomplishments

- Helped recruit for 8 clinical studies via our website, emails and social media channels.
- Embarked on a collaborative initiative to form a consortium with the intent of developing a single, consensus-defined patient-reported outcome measure for alopecia areata.
- Facilitated collaborative write-up and review of the article "Alopecia Areata is a Medical Disease," published in the Journal of the American Academy of Dermatology, to support insurance coverage of treatments as they develop.
- Alopecia Areata Registry, Biobank & Clinical Trials Network grew by 70 participants.
- Planned for the Registry's next phase of growth and accessibility, ensuring its longevity.



WHAT IS ALOPECIA?

\$50  
RYAN  
MILWAUKEE

HEY! LET'S RIDE A THIS WEEKEND! THEN WE CAN EAT!!!!!!  
GR8!

MINAT

## Community Spotlight!

It has been a blessing for me to find NAAF and get involved with our work.

After living with alopecia areata in isolation for 13 years, I attended my first NAAF conference in 2011. Those were 13 lonely years, when I didn't know a single soul who also had alopecia areata, and I lived life feeling utterly alone. That all changed for me when I found NAAF. Suddenly, I was no longer alone; I was able to feel and see that there were other people who not only looked like me, but also understood what I was going through on a deeper level. I knew then that NAAF was going to become a very important part in my life and a catalyst for my healing.

Now, seven years later, this has proven to be true. Not only have I attended the conferences every year and been fortunate enough to be a featured speaker; I have also had the opportunity to meet a lot of extraordinary people and do good for our community. I am proud to have been chosen as a founding member of the Legislative Liaison team and the Advocacy Committee. These groups have been instrumental in attaining significant wins for our community, pushing for the introduction of a bill in Congress that will help get cranial prosthetics covered by insurance and getting the FDA to choose alopecia areata as one of the few

diseases to get a meeting for the [Patient Focused Drug Development Initiative](#).

I have also had the honor to serve on the Board of Directors since 2016, and I became Secretary of the Board in 2017. I am fortunate to have the pleasure to serve NAAF in a leadership capacity alongside the other accomplished and dedicated Board members, and the incredible and hardworking NAAF staff. My involvement with NAAF has given me the confidence to give speeches and write articles about alopecia areata in order to raise awareness and provide a vehicle for [fundraising events](#) in my community, which raise both awareness and much needed funds to support NAAF's mission and goals.

Helping NAAF to help our community has in fact helped *me* find strength and empowerment inside of myself and has given me the ability to cope with my disease while doing good for others.

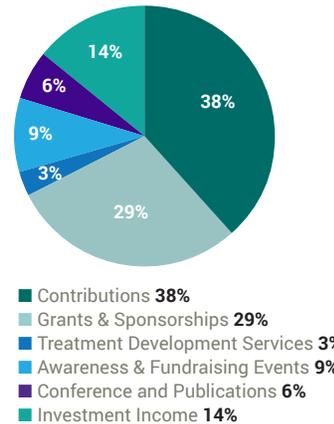
Thank you,  
**DEIRDRE NERO**  
NAAF BOARD SECRETARY



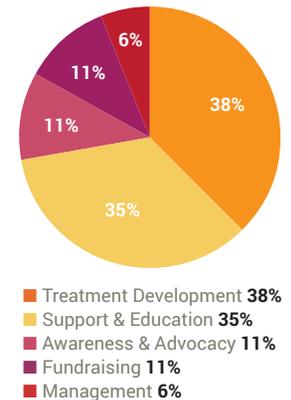
## 2017 Financial Highlights

There is strength in numbers, especially these demonstrating our commitment to support, awareness and research.

TOTAL OPERATING REVENUES  
**\$2,254,000**



TOTAL OPERATING EXPENSES  
**\$2,589,157**



ENDING NET ASSETS **\$3,526,495**

The complete audited financial statements are available on the website at [naaf.org](http://naaf.org) or by mail from the San Rafael office.

## 2017 Donors

**DIAMOND BENEFACTORS**  
**\$50,000-\$150,000**

Harold McNeill Trust  
Sunshine Charitable Foundation

We are grateful for the collective generosity of our supporters. See our full list of donors online at [naaf.org](http://naaf.org).

## Governance

NAAF is governed by a volunteer Board of Directors and advised by two Research Advisory Councils 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 and the Better Business Bureau – Wise Giving Alliance Standards for Charity Accountability.

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