

National  
**Alopecia Areata** Foundation  
**2016 Annual Report**

**ALOPECIA  
AREATA  
MOONSHOT  
WE HAVE  
LIFTOFF!**

“IT’S CLEAR THAT WE ARE  
AT THE BEGINNING OF  
SOMETHING GREAT—A TIME  
WHEN RESEARCH, ADVOCACY,  
AND CARE ARE ALL COMING  
TOGETHER.”

JUSTIN KO, MD, MBA, FAAD AT THE 2016 NAAF PATIENT 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 have lift-off!!

A “moon shot” is an aspirational goal backed by rigorous science. Finding a cure or developing a treatment for alopecia areata is our community’s moon shot, and we are well on our way!

The acceleration we have experienced—the number of biopharmaceutical companies focused on developing a treatment for alopecia areata has increased from one to eleven in just one year—feels like a rocket launch. Treatments showing promise in early trials demonstrate that our trajectory set through research summits over the last six years—our focus on existing treatments for autoimmune diseases with similar genetic profiles—is right on target.

In 2016, the National Alopecia Areata Foundation, working together with an empowered community, also advanced initiatives to alleviate suffering via support, education and advocacy. We plan to bring all of these initiatives together by engaging people living with alopecia areata in all aspects of the research process so the treatments that are developed will be truly meaningful to this deserving community. In this annual report we share just a few of the highlights of a year of unprecedented *engagement, connection* and *responsiveness* across all of the groups who have a stake in this process.

In 2016, NAAF celebrated 35 years of inspiring individuals like you—the individuals who comprise our community. And you inspired *us* to make strides in all of our program areas, achieving goals that were unthinkable just a few short years ago. These advances are even more impressive because we were able to achieve them while maintaining our trademark wise stewardship of resources and sound fiscal and program management.

The stories in these pages are *your* stories. The upward progress made during this full and eventful year was made by the alopecia areata community using *your* knowledge, talents, and strength to overcome a disease that hurts.

When we look back at 2016, we are so grateful for all that was accomplished in just 12 short months. We witnessed triumphs by both longtime NAAF advocates and—just as significant—the next generation, as our young adults stepped into roles of leadership, designing and launching programs to help our children.

One day—and we believe that day is soon—we’ll be able to touch down and say “the Eagle has landed!” Until then, we will guide our craft onward through challenges and triumphs toward a world without suffering from alopecia areata.



MAUREEN MCGETTIGAN  
CHAIR, BOARD OF DIRECTORS



DORY KRANZ  
PRESIDENT AND  
CHIEF EXECUTIVE OFFICER

## NAAF Partners with Two Commercial Campaigns to Help People SeeUs!

In celebration of Alopecia Areata Awareness Month, NAAF accepted an invitation from Revlon to participate in its second Revlon **LOVE IS ON** Campaign. We were one of about 200 nonprofits chosen for this challenge—and the NAAF Community really showed up, sharing their faces, their hearts and their support—and enabling NAAF to place ninth overall on the leaderboard.

We received over 400 donations totaling \$174,538. We also won three interim challenges, with gifts totaling \$6,000, as well as an invitation to meet with the Revlon executives to pitch a collaboration!

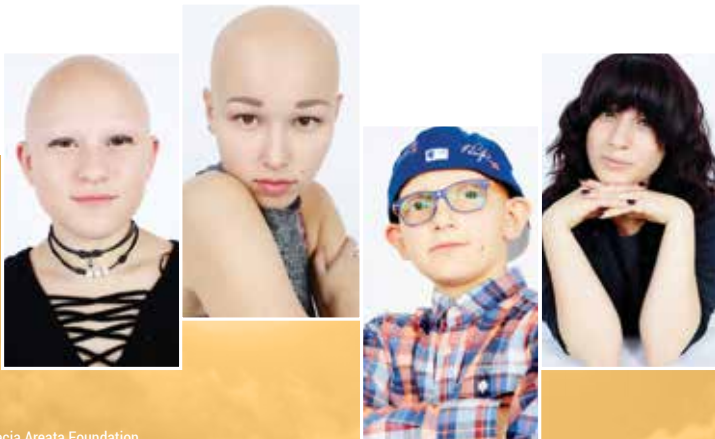
We are so very grateful to you for all of your support.

NAAF was also thrilled to participate in Leo Pharma's **NYSKIN PopUp** event to celebrate visible diversity and difference among people living with alopecia areata and other skin or hair diseases, and to create a photographic census of New York City faces—a natural extension of NAAF's **SeeUs** Campaign.

We were joined by one of the world's top studio photographers, London-based Rankin, the photographer behind Dove's Real Beauty Campaign, and several of our community members showed up to participate and be seen in this impressive awareness-raising event.

We also used this event as an opportunity to interview community members about their experiences living with alopecia areata as we begin to develop a tool to evaluate Patient-Reported Outcomes (PROs), a necessary next step to ensure that the alopecia areata treatments that are developed are meaningful to patients.

We plan to continue to participate in these *PopUp* events. Meanwhile, we thank the NAAF Community for all the wonderful ways you continue to show up!



## Support

Creating community and empowering people living with alopecia areata

### IN THE COMMUNITY

128  
MEETINGS  
HELD BY 62  
VOLUNTEER-  
LED SUPPORT  
GROUPS

64  
TELEPHONE  
SUPPORT  
CONTACTS

### FROM THE OFFICE

5,145  
INQUIRIES  
ANSWERED

1,806  
INFO PACKETS  
SENT

118  
ASCOT FUND  
GRANTS  
AWARDED

### AT THE CONFERENCE

565  
ATTENDEES

60  
SCHOLARSHIP  
RECIPIENTS  
INCLUDING 17  
CHILDREN AND  
TEENS

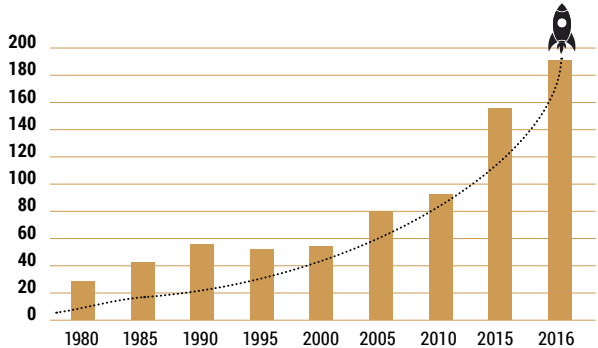
38 YOUNG  
ADULTS  
PARTICIPATED  
IN YOUNG  
ADULT  
MENTORING  
PROGRAM  
DEVELOPMENT  
SESSION

### ONLINE

518,336  
WEBSITE HITS  
414,850  
FIRST-TIME  
VISITORS



SCIENTIFIC PUBLICATIONS ON ALOPECIA AREATA  
2016 ALMOST 10 TIMES THE 5-YEAR AVERAGE IN 1980



## NAAF's Legislative Liaisons Work Toward Insurance Coverage for Wigs

I'm no expert in politics and policy; two years ago I would have told you that I didn't even know the difference between the Senate and House. Today I'm proud to share that, thanks to support and encouragement from NAAF,

I have built a deeper relationship with my congresswoman, Representative Anna Eshoo, who recently wrote me, saying, "You can count on me to do everything I can to find a cure for alopecia areata."

I have also rallied other parents in our support group to write to their congressional representatives to gain co-sponsorship on H.R. 4989, the Cranial Prosthetic Medicaid Coverage Enhancement Act.

Last year my family and I joined over 300 other NAAF members to show solidarity by marching to Capitol Hill to meet with the offices of our senators and representatives. It was a memorable experience for our whole family—not only because we had a chance to try the famous "Senate Bean Soup" at the Senate's restaurant and our kids received free souvenirs at the gift shop, but because we felt empowered and heard. Knowing that our voices matter and that we are not alone gives us strength to combat the stress and anxiety that this incurable disease has brought to our family.

WENDY YU, LEGISLATIVE LIAISON



## Awareness & Advocacy

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

185  
LEGISLATIVE  
LIAISONS

66  
VOLUNTEER-  
LED EVENTS

223  
MEETINGS  
WITH 128  
HOUSE  
OFFICES AND  
55 SENATE  
OFFICES

Thanks to the tireless efforts of  
NAAF's Legislative Liaisons:

■ **Cranial Prosthetic Medicaid Coverage Enhancement Act** is introduced to Congress as bill H.R. 4989. This bill is authored by Representative Jared Huffman (D-CA). Representative Ileana Ros-Lehtinen (R-FL) is the bill's lead and Representative Anna Eshoo (D-CA) is co-lead.

27  
MENTIONS IN  
NEWS AND  
PUBLICITY  
OUTLETS  
AROUND  
THE WORLD  
CREATING  
330 MILLION  
MEDIA  
IMPRESSIONS

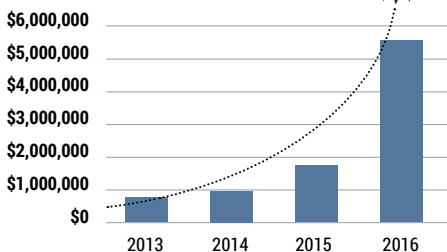
■ **Hill Day, Washington, DC. 400** Conference attendees divide into **25 teams representing 37 states** advocate for H.R. 4989 and increased funding for the National Institutes of Health. **55 Senate offices (55% of the Senate) and 128 House offices (29% of the House of Representatives)** are visited.

■ **Combined visits and online action alerts result in 22 House members** co-sponsoring H.R. 4989.

■ **Since the introduction of our Legislative Liaison program, the alopecia areata research portfolio at the National Institutes of Health has increased from \$820,579 in FY 2013 to \$5,573,896 in FY 2016**—primarily due to the efforts of our research community and legislative outreach, and support from the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

■ **3 Young Adults** worked to develop HARA Curriculum and Training.

NIH ANNUAL INVESTMENT  
IN ALOPECIA AREATA



## NAAF Works to Bring the Patient Voice and Value to Research and Clinical Care

It is fair to say that our patient community, at its core, are supporters of science and research advancement. Who does not want to advocate for the discovery of why they have a disease, how to cure it, and how to prevent anyone else from getting it? So they rally for

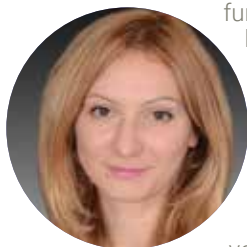
research, contribute to fundraisers, make and bake cookies, sometimes even go knocking door-to-door.

Our patients should have a crucial and active voice in the design of medications. What

scientists, physicians and pharmaceutical companies are finally realizing is that the future research process is going to be intricately driven by the involvement of patients. What has brought on this change is the simple fact that no one knows what it's like to walk in the patient's shoes every day. And as much as the physicians know how to diagnose, as much as the scientists try to come up with answers, they need to know what is important to the patient because research has still not answered many of the questions that patients and physicians face.

Patients are as important in planning the study as we are in conducting it. NAAF's goal is to inspire and equip patients to lead the development and distribution of key research outcomes, from answering lengthy survey questions to supplying data and samples through the Registry or reviewing grants. The advancements that researchers have made regarding alopecia areata would have been impossible without the patients' help. The newly available quality of life surveys will help us describe the burden of alopecia areata in their daily lives, with the hope of gaining understanding by governing bodies, insurance companies and researchers alike. The future will bring more ways to get involved as the concept of patient engagement takes a strong hold, and we can find what is likely to work from treatment development to care delivery.

NATASHA A. MESINKOVSKA, MD, PHD,  
CHIEF SCIENTIFIC OFFICER





## Treatment Development

Supporting research to find a cure or acceptable treatment

**2-DAY**

Research Summit is held to set strategic direction with **120** participants representing **40** academic institutions and research centers across the globe.

**\$427,000**

in grant awards support **9** basic, translational, and clinical research projects in alopecia areata.

**2** travel grants totaling **\$2,000** support young investigators.

Collaborative relationships are cultivated with

**11** bio-pharma companies.

■ Helped recruit for 8 clinical studies via our website, emails and social media channels.

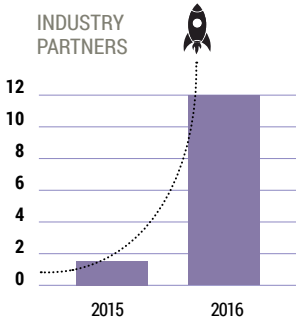
■ Embarked on a collaborative initiative to form a consortium with the intent of developing a single, consensus-defined patient-reported outcomes instrument for alopecia areata.

■ Facilitated collaborative write-up and review of the article "Alopecia Areata is a Medical Disease" to support insurance coverage of treatments as they develop.

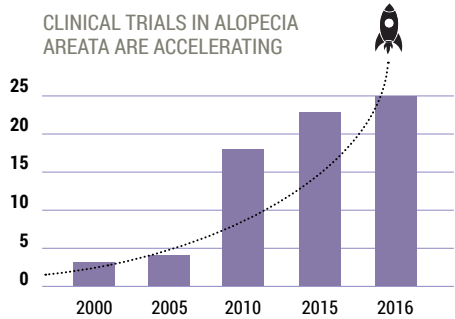
■ Alopecia Areata Registry, Biobank & Clinical Trials Network grew by 70 participants.

■ Planned for the Registry's next phase of growth and accessibility, ensuring its longevity.

INDUSTRY PARTNERS



CLINICAL TRIALS IN ALOPECIA AREATA ARE ACCELERATING



## Community Spotlight!

Lucy, our 7-year-old daughter, was diagnosed with alopecia universalis at 10 months old. We had never known anyone with alopecia. After searching for support, we discovered NAAF and attended our first conference as a family. The support NAAF provided was amazing. After seeing Lucy's confidence and self-esteem grow by connecting with other children with alopecia, we knew immediately that this foundation would be important in her lifelong journey.

Lucy was given the opportunity to go to New York for the NYSkin photoshoot. This turned out to be one of the highlights in her life to date, as her picture was later chosen for the cover of the NAAF newsletter.

NAAF is at the forefront for research and treatment for alopecia. I am so inspired by its hard work and dedication to people living with this disease that I decided to become a Health and Research

Ambassador (HARA) with NAAF to increase its outreach in the community.

Our hope is that Lucy lives a full and happy life with her alopecia, but our goal is for her to have an option for treatment if she ever wishes to. NAAF shares the same vision that we have for our daughter, so we will continue to support NAAF personally and financially. Our family is blessed by the strength Lucy has gained from NAAF.

Thank you,

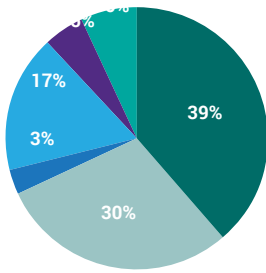
**KELLIE, CORY, LYDIA  
& LUCY DEFFENDALL,**  
COMMUNITY MEMBERS



## 2016 Financial Highlights

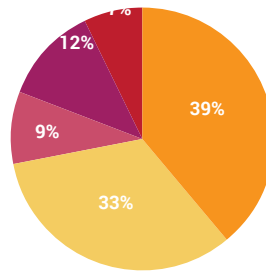
There is strength in numbers, especially these demonstrating our commitment to support, awareness and research.

TOTAL OPERATING REVENUES  
**\$2,501,003**



- Contributions **39%**
- Grants & Sponsorships **30%**
- Treatment Development Services **3%**
- Awareness & Fundraising Events **17%**
- Conference and Publications **5%**
- Investment Income **6%**

TOTAL OPERATING EXPENSES  
**\$2,375,021**



- Treatment Development **39%**
- Support & Education **33%**
- Awareness & Advocacy **9%**
- Fundraising **12%**
- Management **7%**

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.

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