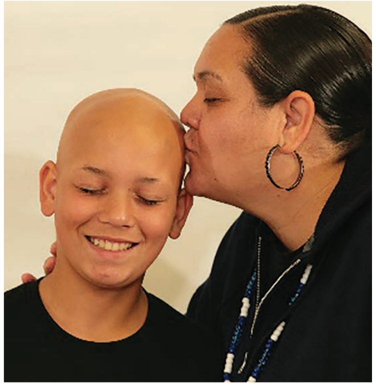
National Alopecia Areata Foundation

A DECADE OF ACHIEVEMENT



2019 Annual Report

National
Alopecia Areata
Foundation

SINCE 1981 THE NATIONAL ALOPECIA AREATA FOUNDATION has been raising awareness, providing support and advancing research for alopecia areata. Yet it was this last decade in which NAAF and the community we serve made the biggest leaps in research, the boldest innovations in advocacy, and the broadest sweeps in support and awareness.

Consider where we were just ten short years ago. As 2010 dawned, there was no understanding of the genetic architecture of alopecia areata. Most members of Congress had never heard of this type of autoimmune hair loss. Children with the disease often felt they had no one who understood what they were going through. Very few, if any, celebrities were open about having alopecia areata.

Now look where we are today.

Research breakthroughs revealing genetic similarities between alopecia areata and other forms of autoimmunity have prompted clinical trials that show treatments for these diseases are effective for some people with alopecia areata. This success has spurred biopharmaceutical companies to focus on developing alopecia areata treatments for the first time ever. Eight companies are now driving toward treatments with clinical trials underway.

Our Legislative Liaisons have cultivated Congressional champions resulting in bills in the House and Senate that, if passed, will significantly help the alopecia areata community — and everyone who will benefit from insurance coverage of wigs for medically-induced hair loss.

NAAF's Youth Mentor program means more and more young people with alopecia areata know they're not alone.

And more personalities from the sports and entertainment world use their celebrity to acknowledge their own alopecia areata and spread awareness so more people can get help, feel empowered and go on to help others.

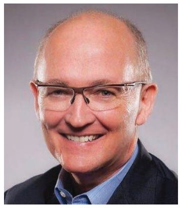
Of course these developments did not happen overnight. But by any metric, the period of 2010-2019 was a highly productive era for NAAF and our community as we drive toward the following impact goals:

- Advance research so that, by 2022, there are two treatments approved by regulatory authorities for alopecia areata that are effective, safe, affordable and easy to use. (#2in2022)
- Increase our reach so that everyone seeking support is connected in ways that are meaningful and empowering to them and knows they are not alone. (#NotAlone)
- Drive our awareness campaigns so that everyone recognizes and understands alopecia areata. (#KnowingAlopecia)

We look forward to what we can accomplish over the next ten years — and hope you'll be with us every step of the way.

Debora Pellicano

Debora Pellicano
CHAIR, BOARD OF DIRECTORS



Andy Bryant

Andy Bryant
ACTING CHIEF EXECUTIVE OFFICER

2010

SUPPORT/AWARENESS

Kayla Martell is crowned Miss Delaware and uses alopecia areata as her platform.

RESEARCH

Dr. Angela Christiano's Genome Wide Association Study identifying eight genes that contribute to alopecia areata is published in Nature; NAAF's early support of Dr. Christiano is instrumental in bringing about this groundbreaking discovery.

NAAF initiates the Alopecia Areata Treatment Development Program.

ALOPECIA AREATA Treatment Development Program

NAAF organizes a Clinical Research Summit on the Immunology of Alopecia Areata.

2011

SUPPORT/AWARENESS

The Team Up awareness program, bringing alopecia areata communities together at sporting events, is established.

RESEARCH

NAAF coordinates alopecia areata incidence, prevalence and quality of life studies and funds the development of a Core Uniform Protocol for clinical trials.

WHEN I WAS FIRST DIAGNOSED WITH ALOPECIA UNIVERSALIS IN 2013, *I thought that I would never be happy again. The sense of loss was profound and I struggled to imagine a life where I would have no hair on my head or anywhere on my body. Fast forward to 2020 and I cannot imagine life any other way! I credit this change in my thinking to NAAF and the support that I have received over the years.*

Alopecia can be isolating as you stand out in a way that is not comfortable. With support from my family and friends, I was able to come to terms with my baldness. I had attended a few NAAF support group meetings in Houston and jumped at the opportunity to lead the meetings when there was an opening in 2018. I still remember being nervous when it was time to lead my first meeting. I will never forget what my boss told me: serving others will help you heal. I live by that code to this day.

Each meeting that I lead helps me grow. And more than that, it helps others know that they are not alone. We have cried at our meetings, laughed together, and shared tips and tricks on living bald.

As a Support Group Leader, I have met with countless parents who struggle with coming to terms with their child's initial alopecia diagnosis. Many blame themselves and feel they did something wrong. As a parent myself, this is heartbreaking for me to hear. Some parents see me completely bald and get sad that their child may grow up to be bald like me. I try to give them courage by sharing my life with them: I love my life, have a great support system, and I just happen to be bald.

Shamsha Damani
SUPPORT GROUP LEADER

2012

SUPPORT/AWARENESS
Webinar on How to Start & Run a Support Group is made available.

ADVOCACY
NAAF drives selection of alopecia areata as one of 39 diseases to be considered for targeted assistance through FDA's Patient-Focused Drug Development Initiative.

11 members of Congress write a letter to the FDA urging the agency to develop industry guidance – a blueprint for development of treatments.

The Legislative Liaisons program is established, training community members to initiate and grow relationships with the offices of their elected officials.

RESEARCH
NAAF assumes financial responsibility of the Alopecia Areata Registry to leverage data and samples after federal funding ends.

NAAF organizes a Research Summit on the Immunology and Clinical Science of Alopecia Areata.

SUPPORT

CREATING COMMUNITY AND EMPOWERING PEOPLE LIVING WITH ALOPECIA AREATA

2,043 people participate and are helped by 177 NAAF support group meetings around the country.

2,009 new posts created by 1,590 members of the alopecia areata community of the online SmartPatients organization.

1,300 Ella dolls are shipped, and 151 are assisted with wig purchases by grants from NAAF.

616 people attended the annual NAAF conference. 90 attendees (including 40 families and 31 children) receive scholarships helping pay for a portion of the cost.

194 Mentors and 214 Mentees participate in NAAF's Youth Mentor program resulting in 90 matches.

2013

SUPPORT/AWARENESS

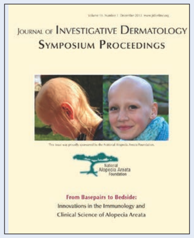
NAAF is one of only 3 organizations selected by Mattel to receive and distribute "Ella," Barbie's friend with no hair.

ADVOCACY

First Hill Day brings the new Legislative Liaisons to Washington, DC.

RESEARCH

Reports from NAAF's 2012 Research Summit are published in the prestigious *Journal of Investigative Dermatology.*



Journal of Investigative Dermatology
Symposium Proceedings

National Alopecia Areata Foundation

From Basepairs to Bedside:
Innovations in the Immunology and Clinical Science of Alopecia Areata

IT WAS APRIL 2019, WHEN I PICKED UP A COPY OF NAAF'S NEWSLETTER.

I had always seen this in my house but honestly never had the courage to read it other than seeing the cover page. But somehow, I started flipping pages and saw the Legislative Liaisons program being mentioned. Immediately I wrote an email to Gary Sherwood asking about this program, and then very soon we talked on the phone. I appreciated the way Gary explained the program to me and I felt like I too could make a difference in the alopecia world, a condition I myself have suffered from for four years.

I felt confident, and that week itself created an alopecia presentation showing my journey and supporting NAAF's vision. I reached out to my congressman and was amazed by the way my message was received and appreciated. I then participated in NAAF's 2019 Hill Day in Washington, DC and met many other alopecia folks as we together advocated for our community on Capitol Hill. I was no longer ashamed of my journey and wanted to talk more. Allison, one of the other young advocates who has been advocating NAAF for quite some time, was there with her mom who suggested we start a new program called "Legislative Mentors." I immediately loved it and became one of the first of these new mentors. This program is to support other youths like me who want to advocate but do not know if, where and how to start. Legislative Mentors meet every month via phone and brainstorm ideas on what was done, what has to be done next and how to do it.

Advocacy has changed me as a person. I feel it has made me much more confident and I am no longer ashamed of my alopecia journey. Thanks to NAAF who trusted me and allowed me to be their advocate.

Tanuj Gupta

LEGISLATIVE MENTOR

2014

SUPPORT/AWARENESS

NAAF's Oral History Project begins with interviews of key figures from NAAF history including Vera Price, Alan Pallie and Donna Murray.

ADVOCACY

The Cranial Prosthetic Medicaid Coverage Enhancement Act is introduced by Rep. Jared Huffman (D-CA).

RESEARCH

Key publications provide the rationale to use Janus kinase (JAK) inhibitors for the treatment of alopecia areata and galvanize industry interest in the field.

The first 4 clinical studies with JAK inhibitors show promise for re-growing hair in people with alopecia areata.

NAAF organizes a Research Summit on Bridging Autoimmune Research to Advance Understanding of Alopecia Areata.

ALOPECIA AREATA RESEARCH SUMMIT

From Targets to Treatments: Bridging Autoimmune Research to Advance Understanding of Alopecia Areata

National Alopecia Areata Foundation

ALOPECIA AREATA Treatment Development Program

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Awareness & Advocacy

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

$2.6 billion increase in funding approved by Congress for medical research programs at the National Institutes of Health which is even more than the amount for which we were advocating. Of that, *$625 million, a $20 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.

293 Legislative Liaisons (*49* coming aboard in 2019) participate in *92* legislative meetings both in district offices at home and in Washington, DC, including our 6th annual Day on Capitol Hill in September, our largest Hill Day yet! Community member Rosie Quinn, age 8, is invited onto the House floor where she meets with Congressional reps and Speaker Nancy Pelosi (D-CA).

16 Congressional members agree to co-sponsor H.R. 3332, a bill which would reclassify wigs as durable medical equipment eligible for Medicare assistance, which is introduced by Representatives Tim McGovern (D-MA) and David Schweikert (R-AZ). NAAF and the alopecia areata patient advocate community also get their first Senate companion bill introduced! S. 2663, written to complement H.R. 3332, is introduced by Senator Richard Blumenthal (D-CT).

4 young community members volunteer to become our first “Legislative Mentors” – young people who will offer advice to other people their age interested in the legislative process, but not yet old enough to become a Legislative Liaison.

594 million impressions created by *48* media mentions of alopecia areata and/or NAAF in such diverse outlets as Rolling Stone, Highlights for Children, Good Morning America, Huffington Post, the BBC, and many others help spread awareness.

64 volunteer-led events spread awareness and raise *$158,453*

2015

SUPPORT/AWARENESS

The See Us awareness campaign is launched, featuring photos of alopecia areata community members from 4 different cities across the U.S.

ADVOCACY

President Barack Obama’s budget request to Congress mentions alopecia areata research activities.

The FDA selects alopecia areata as one of only 24 diseases for a Patient-Focused Drug Development meeting to enhance regulatory assessment and help innovative new drugs receive approval.

FDA

RESEARCH

NAAF initiates the Health and Research Ambassador (HARA) program to educate and prepare the alopecia areata community to bring the patient voice into research design.

Reports from NAAF’s 2014 Research Summit are published in the *Journal of Investigative Dermatology*.

Natasha Mesinkovska, MD, PhD joins NAAF as the Chief Scientific Officer.

THE PAST YEAR HAS BEEN TRULY EXTRAORDINARY IN ALOPECIA AREATA RESEARCH, *for many reasons and due to the contributions of scientists, physicians, clinical researchers around the globe. For the first time, there are multiple ongoing clinical trials open to study new treatments in alopecia areata that have been designed and sponsored specifically for us. This is really a landmark achievement, since these important trials are not simply derivative trials from another inflammatory or autoimmune skin disorders like psoriasis or atopic dermatitis, but instead, these are trials for which alopecia areata is the first indication. This has never before happened in the history of alopecia areata research, and attention must be paid!*


LATEST ISSUE

SPRING 2019

COLUMBIA MAGAZINE

HAIR-RAISING DISCOVERIES

Geneticist Angela Christiano's radical solutions for baldness may point the way to new cancer therapies

The entire alopecia areata community should be extremely proud of this accomplishment. The outstanding research going on around the world in alopecia areata has been so exciting in the past year — ranging from new immunological findings, new cell types involved in the immune response, genetic factors in patients that make them susceptible, new clinical trial instruments to capture patient-reported outcomes, new ways to measure and capture hair regrowth — all of this is just the beginning and provides the foundation.

But the research itself is not enough. It is our collective efforts as a community — our NAAF village — that have moved mountains this year. Together with the awareness you have all helped to create about the need for FDA-approved treatments for alopecia areata have captured the attention of both large and small pharmaceutical companies and compelled them to pursue new treatments for us, our community, our families, our children. It is not unrealistic to dream that our first treatments may reach FDA-approval in the very near term future of just a couple more years. How amazing is that!?!

For this, you should all be so very, very proud and indeed so grateful for all we have accomplished as a family — the extended family of NAAF.

Angela M. Christiano, PhD
COLUMBIA UNIVERSITY, NEW YORK NY

2016

SUPPORT/AWARENESS

Community member Jenny Knopski organizes a flash mob in Times Square.

NAAF's first Oral History film, *Everyone Looks Like Me* (a history of the NAAF conference), debuts at our conference in Washington, DC. Two more Oral History films are debuted at the 2017 and 2018 conferences.

ADVOCACY

The National Institutes of Health/National Institute of Arthritis and Musculoskeletal and Skin Diseases' alopecia areata research portfolio increases from $820K in FY2013 to $5.6 million in FY2016.

NIAMS

RESEARCH

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

NAAF organizes a Research Summit on Building and Crossing the Translational Research Bridge in Alopecia Areata.


ALOPECIA AREATA RESEARCH SUMMIT

Building & Crossing the Translational Bridge

FINAL PROGRAM GUIDE

Monday, November 14 – Tuesday, November 15, 2016
New York Academy of Medicine, New York City, USA

Summit Co-Chairs

Angela M. Christiano, PhD
Columbia University Medical Center, New York, NY

John E. Harris, MD, PhD
University of Massachusetts Medical School, Worcester, MA

Maria K. Hordinsky, MD
University of Minnesota Medical School, Minneapolis, MN

Hosted By

National Alopecia Areata Foundation

ALOPECIA AREATA

2017

SUPPORT/AWARENESS

The Youth Mentor program is established, connecting children living with alopecia areata and their parents to dedicated young adult mentors to formulate lasting bonds while providing support and guidance.

The Concert of Voices in Nashville features a night of performances from musicians, spoken word artists, and stand-up comedians with alopecia areata.

ADVOCACY

The FDA hears from 370 patients at the Alopecia Areata Patient-Focused Drug Development meeting at FDA headquarters in Silver Spring, MD.

RESEARCH

17 Health and Research Ambassadors mobilize 420 people across the country though community training sessions on patient-centered outcomes and comparative effectiveness research.

The FDA grants fast track designation for CTP543, an oral JAK inhibitor, for the treatment of alopecia areata.

Phase 2 clinical trials for alopecia areata are underway with a target enrollment of more than 650 patients.

Reports from NAAF's 2016 Research Summit are published in the *Journal of Investigative Dermatology*.

TREATMENT DEVELOPMENT PROGRAM

SUPPORTING RESEARCH TO FIND A CURE OR ACCEPTABLE TREATMENT

252 researchers, clinicians and interested professionals, including 151 biopharmaceutical industry representatives from 28 different companies, participate in the first joint Alopecia Areata and Atopic Dermatitis research symposium exploring the similarities and differences between these two complex skin diseases.

$464,589 in research funding through current grant awards and future commitments support 10 basic, translational, and clinical research projects in alopecia areata.

6 Health and Research Ambassadors, 6 key opinion leaders and 12 industry representatives participate in 2 roundtable meetings focused on health economics, patient engagement and policy analysis.

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

4 travel grants totaling $6,100 support young investigators attending a scientific conference to present research related to alopecia areata.

2018

SUPPORT/AWARENESS

The *What's My Super Power* Awareness Month challenge features alopecia areata community members of all ages sharing their special strengths.

RESEARCH

The 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.

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

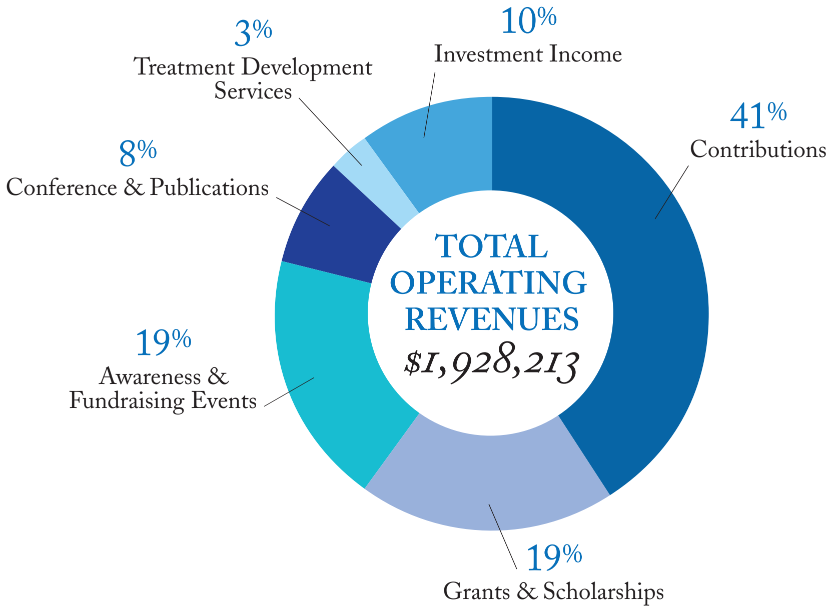
FDA grants breakthrough therapy designation for PF-06651600, an oral JAK inhibitor, for the treatment of alopecia areata.

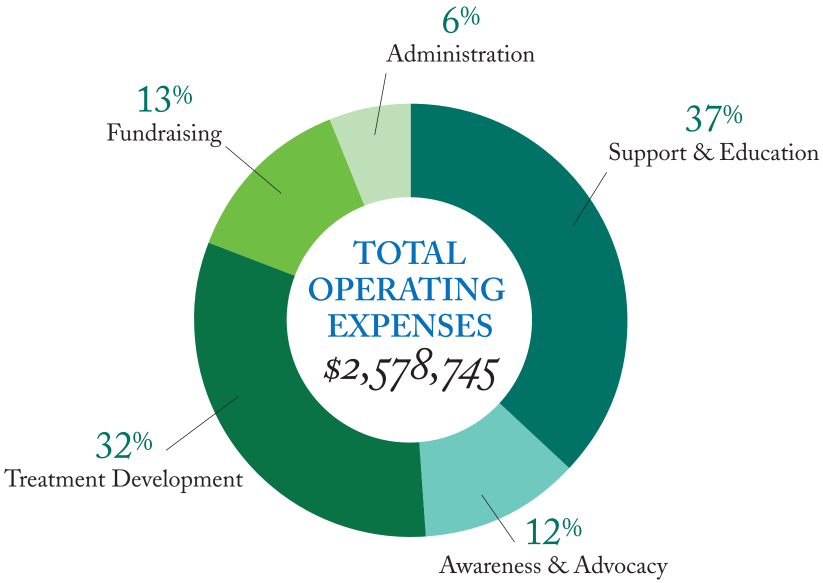
NAAF coordinates publication of the article *Alopecia Areata is a Medical Disease* to help elevate the significant impacts of alopecia areata and move the public agenda forward.

NAAF organizes a Research Summit on Forging the Future of Alopecia Areata.

2019 FINANCIAL HIGHLIGHTS

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





ENDING NET ASSETS

$1,999,022

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

2019

SUPPORT/AWARENESS

NAAF creates postcards for doctors' offices.

Hair falling out? Feeling self-conscious? Loss of identity? You are not alone!

6.8 million people in the US are affected by alopecia areata with a lifetime risk of 2.1%

The National Alopecia Areata Foundation is here for YOU. Our purpose is to serve the community of people living with this autoimmune disease that results in hair loss and, often, emotional pain:

- Connecting you with meaningful support – online, through peer-to-peer mentorship, support groups and conferences;
- Advocating and raising public awareness to enhance how alopecia areata is perceived and approached;
- Driving research to find a treatment or a cure.

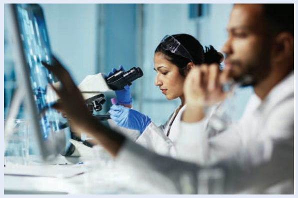
National Alopecia Areata Foundation

ADVOCACY

Our first Senate companion bill, S. 2663, which would reclassify wigs as durable medical equipment eligible for Medicare assistance. is introduced by Sen. Richard Blumenthal (D-CT).

RESEARCH

Large-scale phase 2 and pivotal phase 3 clinical trials for alopecia areata are underway with a target enrollment of more than 3,000 patients.



DONORS

INDIVIDUAL, FOUNDATION AND CORPORATE SUPPORT 2019

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.

January 1, 2019 – December 31, 2019

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$150,000–$249,999

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$50,000 –$149,999

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The Gallagher Family Foundation

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