A YEAR LIKE NO OTHER





NATIONAL ALOPECIA AREATA FOUNDATION 2020 ANNUAL REPORT

hen 2020 began, prospects were bright for the alopecia areata community. The National Alopecia Areata Foundation (NAAF) was finalizing brochure copy, t-shirt designs, and special guests for its annual patient conference in Washington, DC. Most auspicious was Representative Ayanna Pressley (D-MA) announcing that she herself had alopecia areata, presaging what looked like a transformative year.

And 2020 was transformative—but not in ways we were expecting. When COVID-19 pandemic restrictions required the NAAF staff to begin working from home in March, everyone assumed that this condition would only last a few weeks and things would return to normal by April. But as it soon became apparent that the situation was even more serious than first imagined, NAAF and the alopecia areata community learned to adapt, innovate and join forces as never before.

This is the story of how we were able to persevere, push forward, and even thrive in the midst of not only a global pandemic but a change in NAAF leadership. Despite tremendous hurdles, the NAAF Conference was held online, virtual support groups were able to broaden their outreach, achievements in research continued unabated, and legislative advocacy reached new levels of progress.

History will remember 2020 as a watershed year for many reasons. It was a turbulent, trying and memorable twelve months for the entire world, but NAAF and the alopecia areata community continued to bond together and show up for each other when things looked their most dire and uncertain. When you read these pages, you'll see why we believe 2020 was a year we can all be proud of.

Debora Pellicano CHAIR, BOARD OF DIRECTORS

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ACTING CHIEF EXECUTIVE OFFICER

Let he past 365 days were difficult for most. We all faced the consequences of a prolific virus, personal losses, social isolation. . . . And, on top of all of that, some of us dealt with hair loss due to alopecia areata. More than ever, this past year I needed an outlet to feel good and do good. I had thought about starting a support group before—and in my mind's eye, it had always looked like a room full of people sitting closer than six feet apart, eating snacks, and knowing what the bottom half of each other's faces looked like. But in this year, we would have to settle for a virtual conference room.

Consequently, being able to virtually share the past year with other alopecians was one of the greatest blessings I have had. During a time when virtual meetings were a dime a dozen, signing into our meetings each month never felt like work. Our meetings were a time to connect in a way that we all wanted and needed to; they were our social network in a time of social isolation. And there were unexpected positives: group members were no longer bound by driving distances or busy schedules. We ended up having attendees from all across the United States, which was a further reminder that none of us are dealing with alopecia areata alone.

For me, personally, the best outcome of our monthly meetings was a chance to talk to people about "alopecia areata problems" and not about "pandemic problems." This was grounding. It served as a reminder that, amidst all of the worldwide happenings, our daily lives continue—as do our daily stressors. And those stressors deserve to be talked about and addressed—an idea that has sometimes been forgotten in busier years.

A common theme in our group discussions was that we cannot control whether we have alopecia areata or not, but we can control how we manage it. Likewise, there was a lot that was out of our control over the past year—but having a support group gave us all the opportunity to share how we manage the aspects of alopecia areata that we can influence.



Diana Smith SUPPORT GROUP LEADER

CREATING COMMUNITY AND EMPOWERING PEOPLE LIVING WITH ALOPECIA AREATA

306 People attend Virtual Gains, the first NAAF Conference held entirely online.

1,008 Brave Barbie dolls are shipped to alopecia areata families around the world.

625 People participate in and are helped by 113 NAAF virtual support group meetings held around the country despite the COVID-19 pandemic.

992 Phone and email inquiries are answered.

212 Mentors and 230 Mentees participate in NAAF's Youth Mentor Program resulting in 100 matches.



In the midst of looking for treatments and ways to get hair enhancements, I discovered NAAF, and was thrilled to learn about its advocacy arm. As someone who has struggled with both the emotional and physical tolls of living with alopecia areata, I wanted to help others who have struggled but lack support. I wanted to formally advocate for them and enact change.

Thankfully, the NAAF community welcomed me with open arms, and I have been able to do just that. I have attended Capitol Hill Days both online and off-line, advocating for our alopecia community amongst our nation's legislators in Washington DC, and have served as a Legislative Mentor along with other teenagers from all over the country. This past year has been a year unlike any other, and while it was difficult not seeing everyone in person for Hill Day, it was still amazing to meet virtually with legislative staffers and seek to gain their support for our bill; the experience really spoke to the power of NAAF. The Legislative Mentors were able to make significant progress this year by speaking to local representatives and creating a video to inspire and educate the next generation of Legislative Mentors; we have all kept busy and focused despite these uncertain times!

On a recent call with the other mentors and NAAF Communications Director Gary Sherwood, I learned now that I am eighteen, I can transition from being a Legislative Mentor to a Legislative Liaison. I will be the first Legislative Mentor to do this, and as someone who has spent the majority of my time working with other teenagers, I look forward to exploring a new approach to advocacy with NAAF. I couldn't be more excited and proud to start this new chapter, and I plan to bring my experiences and ideas with me as I start this new journey.



Sophia Soltanian LEGISLATIVE MENTOR

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

Representative Ayanna Pressley (D-MA) announces she has alopecia areata in January and immediately begins championing the alopecia areata community in interviews, co-sponsoring H.R. 3332 (see below), making a special introductory video for the NAAF Conference, and addressing the House of Representatives on the subject of alopecia areata.

A \$1.25 billion increase in funding is approved by Congress for medical research programs at the National Institutes of Health. Of that, \$634.29 million, a \$9.4 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.

309 Legislative Liaisons (including 16 who came aboard in 2020) participate in 83 legislative meetings, the majority of which are held online, including 19 virtual Capitol Hill Day meetings conducted during the NAAF Conference.

32 Congressional Members agree to co-sponsor H.R. 3332, the House bill which would reclassify wigs as durable medical equipment eligible for Medicare assistance and which was introduced by Representatives Tim McGovern (D-MA) and David Schweikert (R-AZ). Meanwhile the Senate companion legislation, S. 2663, introduced by Senator Richard Blumenthal (D-CT), gains its first 3 co-sponsors.

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

6 Legislative Mentors, young people interested in the legislative process but not yet old enough to become a Legislative Liaison, begin holding monthly meetings and create a video for the NAAF Conference urging fellow young people to get involved legislatively. Along with their parents, they participate in virtual meetings with their lawmakers.





Joshua Dobbs of the Pittsburgh Steelers appears on The Doctors to discuss alopecia areata. NAAF also unveils a new Public Service Announcement starring Joshua.

Cedrice Ce represents those with alopecia areata on *The Voice* while NAAF Moscow Support Group Leader Liliya Nugmanova is selected to be one of the faces of Dove's #showus campaign.

483 million Impressions are created by 40 media mentions of alopecia areata and/or NAAF in such diverse outlets as ABC News, the BBC, BCSN Sports, Fox News, Good Morning America, The New York Times, and NIH MedicinePlus magazine, as well as multiple podcasts including Heal Thy Skin podcast out of Australia, The Patient Will See You Now, and Unapologetic Badasses.

25 Events led by volunteers spread awareness and raise \$167,999.

EVELOPMEN

L he past year has been difficult and trying in so many ways. Through all of this, the NAAF community, including its patient members, researchers, physicians, and industry sponsors, found new, creative ways to safely continue critical clinical trials in alopecia areata, provide patient education through the NAAF Virtual Patient Conference in June, and offer vital support groups for people experiencing alopecia areata.

In addition, with NAAF's support, the new concept of Cumulative Life Course Impairment (CLCI) in alopecia areata emerged as an important consideration; it conveys the fact that alopecia areata can negatively alter the trajectory of a person's life—especially when access to proper support and treatments is limited. Dermatology hair loss experts and industry partners nationwide also gathered virtually to develop a new tool to grade severity in alopecia areata that reflects all aspects of the condition and is not based solely on the percent of scalp hair loss.

Thanks to the long-term collective efforts of the NAAF family, we are now on the threshold of having the first FDA-approved treatment specifically for alopecia areata! The magnitude of this accomplishment is immense; it emphasizes the acceptance of alopecia areata as a significant medical entity, provides access to needed treatments for patients, and encourages further investigation into new therapeutic targets for this condition.

The accomplishments of the NAAF community were much-needed bright spots during this year. We remain thankful to NAAF and its members for their incredible dedication and look forward to the future with hope and enthusiasm.



Maryanne Senna, MD HARVARD MEDICAL SCHOOL, CAMBRIDGE, MA

SUPPORTING RESEARCH TO FIND A CURE OR ACCEPTABLE TREATMENT

19 Reports from the 2018 Alopecia Areata Research Summit are published in the *Journal of* Investigative Dermatology Symposium Proceedings reaching 5,215 subscribers.

 $\$198,\!273$ in funding through current grant awards support 8 basic, translational, and clinical research projects in alopecia areata.

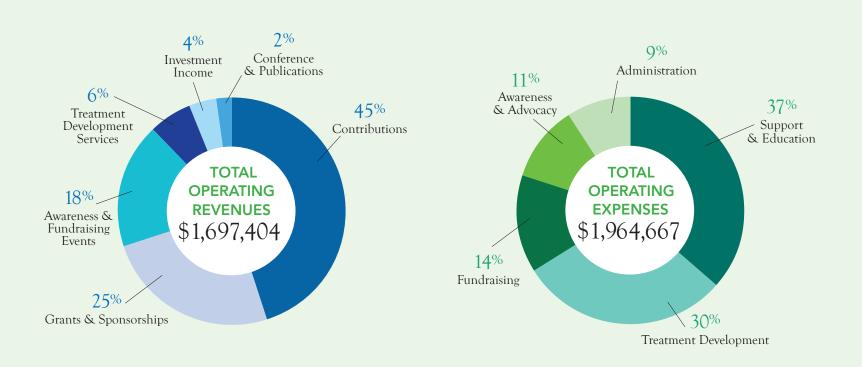
2 Health and Research Ambassadors, 7 Key Opinion Leaders and 7 Pharmaceutical Industry Representatives participate in a roundtable focused on assessing the cumulative life course impact of alopecia areata and addressing the gaps.

7 Clinical Studies gain recruits via NAAF website, emails, and social media channels.

7 Student Internship Awards totaling \$8,000 support young investigators conducting short-term research projects focused on alopecia areata under the supervision of experienced investigators.



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



\$1,732,659

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.

January 1, 2020 – December 31, 2020

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