



## NATIONAL ALOPECIA AREATA FOUNDATION

### YOUTH MENTOR PROGRAM 2018 PROGRESS REPORT

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## YOUTH MENTOR PROGRAM

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In 2017, NAAF's Young Adult Community worked together with NAAF Staff to design a program that would not only help kids find tools to navigate their specific situation, but also answer questions parents might not normally be able to ask their own child. During NAAF's Annual Patient Conference, young adults (ages 17-30) are able to sit down and have a conversation with the tweens and teens in the Kids Camp about the reality of living with alopecia areata. For some kids it was their first time being able to open up about some of their insecurities, and for others it was a perfect chance to offer their own personal anecdotes about standing up for who they are. This experience is life-changing for many. NAAF wants to ensure that children living with alopecia areata and their families have access to this support year-round, wherever they live.

In October 2017, NAAF formally launched the Youth Mentor Program, connecting children living with alopecia and their parents to young adult mentors to formulate lasting bonds while providing support and guidance on living with alopecia areata. Youth Mentors go through an application and screening process, a training program, and receive on-going support from Youth Leaders and NAAF Staff. Mentees and their parents enroll in the program, and are then able to use NAAF's Mentor Match on-line platform to find a mentor in their local vicinity. The mentee then chooses a mentor from the platform and if that mentor is available, a match is made! NAAF then facilitates the meeting and provides support throughout the on-going mentoring relationship. Many mentors and mentees use Skype or Facetime to keep in touch especially when they are not able to find a match close to home.

In January, 2018, thanks to the inspiring leadership of Ernie Kaye, and gifts totaling \$182,452.96 from the Kaye Family and friends, NAAF was able to fully establish and grow the Youth Mentor Program. As we now celebrate the Program's one-year anniversary, we want to **thank you for your incredible support!**

## IMPACT OF KAYE FAMILY & FRIENDS SUPPORT

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At the start of 2018, NAAF's Youth Mentor Program began accepting mentor and mentee applications. Immediately our emails boxes and voicemails were filled with messages from grateful parents that have been looking for a way to extend the support their children receive from others at NAAF's Annual Conference throughout the year! We also heard from mentors who told us they had always wished they had a mentor when they were younger and that they were so happy to be able to reach out to other kids in this way.

*“This mentor match has been an absolute answer to prayer for my teenager. Her mentor is amazing and such an inspiration. I can see them having a life-long friendship! Thank you!” -Elisa M.*

### Mentors and Mentees Enrolled

The Youth Mentor Program received **140 mentor** applications. Of those, 33 mentors have been matched with mentees. Some mentors have 2+ mentees. The Program received **107 mentee** enrollments and of those **54 mentees are matched**.

### Awareness and Outreach

NAAF is working to spread the word about the Program. At the 2018 Annual Patient Conference in Arizona last July, NAAF was excited to offer a workshop to those in our community interested in the program either for themselves or a loved one. Communications Director Gary Sherwood gave a slide presentation outlining the specifics of the program and how mentors are approved after interviews, a background check and training. Two mentors—Nell Sanders (one of the program’s co-founders) and Ebony Jean (an active mentor)—described the experience for themselves, talking about what they are hearing from the young people they are working with, and what they’ve learned through the process of mentoring.

*“The Youth Mentorship workshop provided a space for mentors or interested mentors-to-be to discuss the criteria of the program, alongside the successes and challenges of being a mentor,” recalls Nell. “The workshop allowed for an inspiring and relatable discussion on the ‘mentor life.’ The Youth Mentorship program itself is an invaluable opportunity for connection between both children and young adults living with alopecia, through the building of a strong relationship based in trust, communication, and mutual understanding.”*

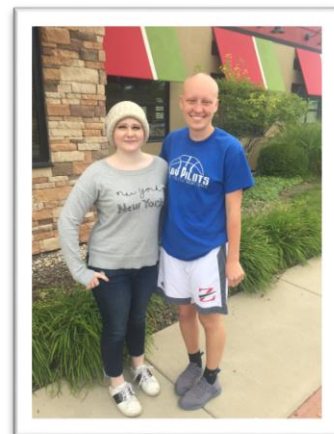
*Ebony adds, “It is vital for our children to have positive influences in their lives, someone who knows exactly what they are facing. Growing up I did not have a role model, so becoming a mentor for the alopecia community is a true honor.”*

NAAF’s outreach also included publishing Youth Mentor stories in our e-Newsletter, *Beneath the Surface* and our print publication *Alopecia Areata News*.

In 2019, we will continue to spread the word about the Program. We have changed the mentor eligibility age to from 17 years-30 years, to 16-years – 30 years, due to community feedback. We will also expand the Program to include a “Peer to Peer” program for people 18 years and older that would like a mentor relationship.

### Program Evaluation

NAAF developed two short survey’s (one for each group) to circulate via Survey Monkey in order to evaluate the impact and effectiveness of the program and learn where the program can improve. The first survey will be sent to mentors and mentees who have been part of the program for at least 6 months in February 2019.



In the meantime, we continue to receive direct feedback by emails like this from the father of a nine-year old girl who joined the Program last fall:

*"I just wanted to give you an update on Jade since we last spoke. We have taken advantage of the mentor program and it's been a wonderful tool for Jade. Katie (our mentor) has been so caring and kind and a true role model for Jade. Jade recently (at 6) decided on her own to shave her head. Our entire family did it with her in solidarity including Amy (her mom). Jade has also become a little social media star with her new Instagram page (@Jades\_Journey1234) which she uses(managed by us of course) to spread love and support any kids who have Alopecia. She already has almost 900 followers in 2 weeks. It's been pretty amazing. It's been shared so much that people throughout the country with Alopecia have reached out to offer support and show Jade love. It's been a wonderful confidence booster for her."*

## MONIQUE'S MENTOR STORY

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I was eight years old, and for the first time in my life, I felt ordinary. As I walked through the hotel lobby in St. Louis, I couldn't shake the feeling that no one was staring at me. Everywhere I looked, people looked strangely like me: everyone was bald.

That was my experience when I first attended the annual NAAF conference, but that same feeling of oneness and joy has stuck me every year since. Growing up with alopecia, the NAAF conferences were always a beacon of light in my acceptance journey. I had patchy alopecia until I was about 10, but when I finally lost the last of my hair and eyebrows, I couldn't wait to show off my new 'do to my camp friends at the next conference.

Outside of the NAAF conference, though, I didn't have anyone I felt I could truly relate to when it came to my alopecia. I grew up in the suburbs of southeastern Virginia, and at the time, local support groups were too far away for me to attend. For a while, the conferences filled me with so much joy and confidence that I could get through the ups and downs of alopecia and make it to the next year. However in the thick of high school, when dealing with my alopecia was the most difficult, NAAF conferences were almost *too* good. As soon as *What a Wonderful World* started playing during the closing ceremony slideshow I cried my eyes out—and didn't stop until the next day. The walk through the airport to get home was the worst part; the stares that I welcomed giddily with my crew during kid camp expeditions felt sharp and painful alone. Within a few days I readjusted to my everyday life with alopecia, but the stark contrast between NAAF and the "real world" was a lot for a kid to deal with. As I grew up and learned how to better cope with my alopecia in the interim, NAAF conferences continued to keep me grounded and returning home wasn't as hard as it once was.

Now I'm 23, I live in the real, real world (post-college), and I still attend conferences almost every year. As of this past April, I'm also part of NAAF's *incredible* Youth Mentoring Program where young adults like me are paired up with kids and teens with alopecia. After making it through the application process, I posted a short "about me" bio on the website where kids and their parents search for mentors by location and get connected. Within about a week of submitting my bio, I was matched with Shelby, a 9-year-old girl who lives about 35 minutes away from me, and her mom and I swapped schedules to set up our first meeting.

We've met every month since, drinking Starbucks, getting a pedicure, and recently having our heads hennaed together! Shelby and I don't always talk about being bald—we mostly just talk about her softball team, school, and friends—but just knowing that we both understand what it's like is enough. Having this relationship is the coolest reminder for both of us that there's someone else out there, who is not even that far away, and it helps make NAAF and the real world not seem so far apart. I love this opportunity to give back to the alopecia community—and it's fun and easy with Shelby's endless supply of energy. I am really looking forward to watching her grow, and I am proud to play whatever role I can in her alopecia journey.

## 2018 YOUTH MENTOR PROGRAM BUDGET

BUDGET CATEGORY	DESCRIPTION	COST
<b>Kaye Family &amp; Friends Support</b>	Support raised from Ernie's Appeal	<b>\$ 182,452.96</b>
<b>Personnel</b>		<b>\$35,242.00</b>
<b>Awareness/Marketing</b>	Social Media advertising, marketing materials	<b>\$ 6,000.00</b>
<b>Consulting</b>	Match platform/ IT	<b>\$ 400.00</b>
<b>Other Costs</b>	Conference AV, Training Room	<b>\$ 670.00</b>
<b>Verification Services</b>	Background check, verification service vendor (\$20 per check)	<b>\$ 2,442.40</b>
<b>On-line Training</b>	Annual Fee & Training costs	<b>\$ 1,800.00</b>
<b>Total Program Cost</b>	2018 YM Program Costs	<b>\$ 46,554.40</b>