National
Alopecia Areata
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The Power of Peer Support: Teens with Alopecia Areata Supporting Each Other
Mary Wills, MSW, LISW-S
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JUDY WILLIAMS: (00:00)
Welcome to the National Alopecia Areata Foundation's webinar, The Power of Peer Support, Teens with Alopecia Areata Supporting Each Other. Joining us today is behavioral health therapist Mary Wills, and I am Judy Williams, Director of Community Support for NAAF

Before we start the webinar, I'd like to cover a few housekeeping details. We have disabled chat for this webinar session. Please post questions for Mary in the Q &A section. Please keep your questions general for the benefit of all audience members. This webinar is being recorded. All registrants will receive a link to the recording via email. And finally, please share your feedback with us. At the conclusion of the webinar, a link to a short survey will pop up in your browser window.

Please complete the survey there. We use your input to plan for future webinars. Note that live captioning is available for this webinar. To turn on the captions, click the CC Show Captions button on the Zoom toolbar. Captions will appear automatically at the bottom of your screen. And this webinar is part of NAAF's You Are Not Alone Education and Empowerment Webinar Series.

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Before we get started, I'd like to tell you a little bit about NAAF and our mission. The National Alopecia Areata Foundation is the leading advocacy organization for alopecia areata. NAAF's mission is to drive research, to find a cure and accessible treatments for alopecia areata, support those who are impacted and educate the public about the disease. NAAF's vision is an empowered community with the choice to embrace or live free of alopecia areata. To learn more about NAAF support resources, and research and advocacy activities, or to join us as an advocate or a supporter, please visit our website at NAAF.org. We know that it can be confusing to hear a lot of the terms used to talk about alopecia areata, patchy, diffuse, ophiasis, totalis, universalis, mild, moderate, and severe. The NAAF team wants you to know that even though there are many words used, they all refer to one disease, the autoimmune disease alopecia areata. That's what we are here to talk about today. And now on to today's webinar, the power of peer support, teens with alopecia areata supporting each other. We are very pleased to have Mary Wills presenting today's webinar. Mary is a behavioral health therapist and licensed social worker based in Cleveland.

Having lived with alopecia areata for most of her life, Mary brings both professional expertise and personal insight to her work. She has extensive experience supporting children, adults, and families as they navigate mental health challenges with a particular focus on the emotional impact of chronic illness. Mary is deeply committed to creating a safe, supportive space where individuals can feel seen, understood, and empowered.

She serves as a Midwest regional support group leader with NAAF and also leads both the teen girls support group and the Cleveland virtual support group, helping to foster connection and community among those affected by alopecia areata. And I'll hand it over to Mary. Thank you for being here today.

MARY WILLS: (03:30)
Thank you, Judy, so much for the introduction. I'm going to go ahead and get started with sharing my slides. So hello, everybody. Thank you so much for joining this webinar today. My name is Mary Wills I'm so honored to speak with you about something that can truly change lives and the power of peer support for teens and young adults living with alopecia areata. Today, I want to talk about why connection matters, how friendships and communities can strengthen emotional well-being, how peers can support one another fully, and when additional support may be helpful. Living with alopecia areata can feel incredibly personal, but one of the most healing things people discover is that they're not alone.

So Judy introduced myself. I wanted to say a little bit about myself. I am a behavioral health therapist and social worker in Ohio. I serve as the support group leader through NAAF. I lead the teen girls virtual support group, a Cleveland support group, and I support the efforts in the Midwest region. So today I'm speaking to you from three perspectives. One, as a therapist who understands emotional health and wellbeing.

Two, as someone who's had the privilege of watching young people build confidence, friendships, resilience, and joy through peer connection. And three, as somebody who has alopecia areata. In this picture, I am the second child on the left. wearing purple. I was probably in kindergarten in this picture. And if you look closely, you can see a spot on the very top of my head. So I've lived ~ majority of my life with this disease. was originally diagnosed at two years old.

I have seen firsthand what happens when someone walks into a room and they think they're the only one with alopecia areata and that same person walk out realizing that they have an entire community behind them.

Alopecia areata is often described medically in terms of hair loss, but socially and emotionally, it can affect much more than appearance. Alopecia areata is a visible difference. That difference may lead to unwanted attention, staring, questions, comments, or assumptions. Some people with Alopecia areata experience bullying and others may experience pity or sympathy. Many miss school, events, sports, sleepovers, or opportunities because they feel self-conscious.

Families may also experience a financial stress related to treatment, wigs, travel, or healthcare. And perhaps one of the biggest impacts is isolation. Sometimes people withdraw not because they want to be alone, but because being seen feels exhausting. And that's why peer support matters so deeply. It interrupts the isolation.

Adolescence is already a major stage of growth. It occurs between the ages of 10 through 19. Young people are figuring out who am I, where do I belong, how do others see me, and what do I value? Peer relationships are the most important thing during this time. Friends matter tremendously. Acceptance in a group matters, and so does belonging.

Social media has added an additional layer to this. There's this constant comparison, appearance pressure, and visibility into our lives that other generations did not experience before. When alopecia enters this stage in adolescence, it can feel especially intense. And because it touches our identity, confidence, friendships, and social comfort all at once, that's why support during adolescence can be life-changing.

Young adulthood brings different but equally important development experiences. This age group is 20 to 24. This is a season of building independence, exploring relationships, making career decisions, and finding community. Many young adults ask, who am I becoming? What kind of relationship do I want? And where do I fit in in the world? For someone with alopecia areata, this can bring added concerns around dating, work settings, confidence, and self-image. And at the same time, young adulthood can be a powerful time to reclaim our identity and build authentic connection with others. So peer support can help people realize, I can be confident now, I can belong now, and I do not need to wait until everything feels perfect.

So what exactly is peer support? Peer support is connection with people who understand something because they have lived it too. It's not about having all the answers. It's about saying, get it, I felt it, and you don't have to explain. That kind of connection reduces the shame, fear, loneliness, and anxiety. And research shows that positive peer support can increase overall life satisfaction and patient outcomes.

Peer support reminds us that acceptance often happens within relationships.

So people always ask, how do you support one another? And how can we support each other well? When we're involved in a peer support connection, we want to actively listen without judgment. People do not need solutions. They just need space. We want to share experiences, not comparisons. You can say something similar happened to myself, but we want to try to avoid, know, mine was worse. I want to use empathy instead of advice.

Instead of you should do this or you should do that, we want to try that sounds really hard. Everyone goes through this experience at an individual level. We want to create safe group norms. So confidentiality, kindness, respect, and inclusion.

Sorry. We want to practice boundaries. You're allowed to care without your compassion becoming overwhelming. And that can be boundaries with yourself and with others. We want to celebrate each other's strengths. Alopecia areata is just one part of you. It is not your entire identity. And there are so many other parts of you that make you you. We want to check in regularly with another simple messages that just show that you care and encourage inclusivity. When we're in the room, we want to notice who is quiet, who is new, and we want to invite them in the conversation. Many people, when they're new in these groups or rooms of other people in alopecia areata, they tend to be more quiet. And we just want to kind of help get them out of their shell, invite them to share, and they can share what they choose to share. You can support one another through various avenues, such as social media, the NAAF conference, Walk for Alopecia or support groups. I want to shout out to the Instagram page, Alopecia Justice League. It documents the experience of alopecia areata through the lens of teenagers.

So resilience does not mean never struggling. It just means that you're adapting, recovering, and continuing forward. Peer connection strengthens resilience by reducing the isolation, normalizing the experience, shared coping skills, modeling confidence, building belonging, providing validation, and encouraging growth. And sometimes that courage is contagious. When one person takes a step, others realize that they can too.

So boundaries are incredibly important to peer support. Boundaries mean that we understand what is mine to carry, what is yours to carry, what I want to share and what I want to keep. You do not owe everyone your story. You choose what you disclose to when and to whom, and you can be open some days and you're allowed to be private others. Oftentimes the teens I work with, they write down their responses to common questions that they anticipate to receive and they practice them. That way they're confident when the question is asked on the spot.

So the importance of boundaries, they protect emotional energy. They reduce that burnout. They prevent the over-identifying with alopecia as your only identity. They build self-advocacy. They protect against peer pressure. They create healthier friendships. And boundaries also help support you better, because only you know what's helpful to yourself and what doesn't.

We want to talk about when it is important to seek professional support. So peer support is very powerful, but sometimes additional support is needed. Please seek professional help if you're crying more days than that. If thoughts about alopecia areata consume your day, your functioning has decreased and functioning could be you're having a difficult time getting out of bed, going to school, going to work. You're avoiding life significantly. If you had any thoughts of harming yourself or ending your life or if somebody is hurting you emotionally or physically. And if you need linkage to any resources, please call 988, the National Mobile Crisis Hotline. You can also find a therapist on Psychology Today online, or you can discuss these concerns with your primary care doctor. And sometimes we need multiple types of support to be our best selves, and peer support can complement that professional support while we navigate this experience.

So NAAF offers virtual teen groups. This includes the boys and girls groups for ages 12 to 17, and these are open to anyone in the US. We do have a consent form for the parent or guardian to complete prior to starting. This is just to make sure that the child is between the ages of 12 and 17, they have alopecia, we have the best email addresses to send the Zoom link to, and that the parent agrees to participate.

sorry, the parent agrees for the child to participate in the program. These groups give young people space to talk, laugh, ask questions, and be understood. The content is not always about alopecia areata. We let the teens lead. So oftentimes in the girls group, I mean, they're talking about their favorite artists, the sports that they're in, the activities, if they're in theater.

They talk about their personal goals, applying to college, and what do they want to be when they grow up. It just creates like a safe space for these kids to connect. And we have kids from all over the United States, so it's really cool to see that connection with kids that are very different, very different, you know, communities that they grow up in. You know, oftentimes the teens, join very quietly. We let them start at their own pace but months later, they're encouraging each other, they're opening up, they're participating more. Research shows that support groups for chronic health conditions tend to boost confidence and increase patient outcomes. So this is kind of the magic of peer connection. We really get to watch people grow towards acceptance emotionally, you know, with this disease and navigate some of those challenges that they come across. Some of the girls can give other girls advice of how they, you know, what they did when they experienced this. And if you're interested in the girls group, can email myself, maryalopeciagroup at gmail.com. I will send you the consent form to complete. I co-facilitate with my colleague, Dr. Kate Beard. She is a dermatology resident and she also has alopecia areata. The boys group is led by Rafi Wasserman and Ezra Cohen. You can RSVP to the boys group at rafi.waserman at gmail.com. Rafi and Ezra are in their 20s and they have lived with alopecia areata the majority of their life as well.

So when it comes to support groups, this could be for our young adults. This is a screenshot from the NAAF website. We have support groups in 27 out of 50 states. But some of the groups are virtual, some are in person. So if you don't have a local group near yourself, you can create one. ~ You can also join a virtual group in a different city. These groups are open to anybody. This is a safe space for adults with alopecia areata, the parents of children of alopecia areata, and I have parents of young adults ~ in my group as well. So my group is generally Ohioans because I cater to the Cleveland area. However, we do have people from all over the country who join. We discuss wigs, bandanas, treatment, makeup, and just general life social experiences. It's really a way for people to connect and to share. And you're welcome to speak as little or as much as you would like and what you're comfortable with.

Some people, they'll join my group with an agenda of questions, and other times, some people just wanna listen to others. So if you attend one support group and you feel nervous, that's completely normal. Many leave grateful that they came and they learned something new, and I've been leading my group for years and I learn new things every meeting.

So the Youth Mentor Program is another incredible resource from NAAF. So young people are matched with slightly older mentors who understand the experience. Sometimes confidence is easiest to receive with somebody just a few steps ahead of yourself. All mentors are vetted with background checks and interviews. The family selects the mentor together, and ideally mentors are selected based on location. But sometimes a mentor is virtual, and maybe you guys...meet at the conference or any other physical meeting place. To sign up, we'd email support at NAAF.org.

So the conference is one of the most transformative experiences that many families describe. There are educational sessions, kids programming, friendships, community, and fun. Of course, we have a dance party. But beyond the schedule, conference offers something deeper. It offers belonging and community. People often say it feels like coming home. Many newcomers to the conference state that this is the first time ever meeting somebody else with alopecia areata and then they continue to go for following years. Lifelong friendships are made at this conference. Tears are shed. It's a transformative to see the connections that are shared in the hotel, new friends that are going out to dinner and sitting with each other at the game every year. We have vendors, so you can look at different products. And my favorite booth is the makeup booth where I can get a makeover every day. Registration for the conference is online.

It's a great opportunity to meet others within your age group and from people all over the country.

So events for Walk for Alopecia also creates a visibility, pride, advocacy, and connection. It occurs during Alopecia Awareness Month in September, and this year it is September 26. The Walk is organized in 44 cities in the US, and it's growing. If you want to organize a walk in your city, you can email walk at naaf.org. But to receive support, and you can also receive support on organizing that walk.

This is a chance to meet other teens or young adults your age. And last year I actually met somebody who lives on my street who I have never seen before in my neighborhood. It was just an example of how common alopecia areata is and how small of a world or community that we live in.

You can also do a walk where you are if you're not in a position to organize a walk. I did this for years before somebody else organized the Cleveland Walk. And it's really just going on a walk on a smaller scale. You you raise money independently and many people choose this option if they don't have a walk near them and they're not able to organize a walk. The walk reminds yourself and your city that this is a community that is strong, growing and supportive.

It also allows families to participate in a meaningful way and to meet one another.

So I've always loved this poem by Shel Silverstein, and I just feel like it relates to those with alopecia areata, masks. She had blue skin and so did he. He kept it hid and so did she. They searched for blue their whole lives through, then passed right by and never knew.

So part of alopecia areata experience is camouflage, and we may not know everybody who has it because they just don't show it outwardly. A few years ago, I worked with a woman who presented bald to work, but she never mentioned to me why she doesn't have hair. I decided one day to go up to her and share that I have alopecia areata, and I felt that if I shared that, that would open up the conversation for her to share if she shares a similar disease.

In that moment, she also shared that she had alopecia areata. She was diagnosed in her 40s. She told me about the experience and it really created a bond between herself and myself because I shared that with her. Although she and I were very different roles, we didn't see each other a lot, it was nice to know that we had that connection. And when I read this poem, it just kind of reminds me of all those connections that we pass by every day, but we never know who else has alopecia areata.

So with that, as we close, I just want to leave you with this. Alopecia may affect your hair, but it does not define your worth, identity, beauty, or potential. Connection heals shame and it builds confidence, and friendship strengthens that resilience. Whether you're a teen, young adult, parent, sibling, or supporter, I want you to know that you have a place here and you don't have to navigate this alone. So I want to say thank you so much for everybody today and I'll see you in Orlando for the 30...

41st, sorry, 41st NAAF Conference. And if have any questions about the programs that we had discussed, you can always email info at naaf.org and navigate those on the website.

JUDY WILLIAMS: (22:20)
Thank you, Mary. I will start asking some other questions. We have some great questions that have been coming in through the Q&A.

And one of the questions does have to do with camp with the, I'm sorry, with the conference. And it's a great question. But I'll let you I'll give them information about the youth camp, how they can connect as well. But it asks, my daughter has alopecia, and she and I are both attending the conference in June. Will there be opportunities for her to meet kids her age 12? She is desperate to have a friend like her. If so,

how and I can share with them a little bit about the youth camp. But can you share about like things you've observed as far as making connections in the conference?

MARY WILLS: (23:07)
absolutely. So yes, your child will meet a ton of friends around that age group. So they do have a kids camp for the minors and they have fun. Okay. So they go to museums, like they do fun stuff. Okay. So us adults, we get to learn. We go to like sessions about what this disease is or support things. absolutely. Like your child would meet other people at the conference their age. And I think

even outside of the conference. So the conference is typically daytime hours, like the activities, but in the hotel, we kind of take it over and you will just see so many teenagers, preteens, running around this hotel in the common areas, making friends, they're taking over the pool. So you absolutely see that, that connection. And I, you know, I...

run the teen girls group. I even see a lot of the kids too that are in the group and I get to meet them for the first time in person which is exciting. And then on Saturday we usually have the dance party and that's definitely a time where the kids can just have fun and be kids.

JUDY WILLIAMS: (24:16)
Thank you, Mary. And as Mary mentioned as well, we do have a youth camp at the conference, and it's designed for children ages five to 17. And there's three age groups separated by age groups, like five to 10, and then it's 11 to 13, and then 14 to 17. And these groups, they get to meet other kids who have alopecia areata.

as well as siblings and they have different activities also going, you know, different activities that this camp provides. But this year we're also providing some special sessions just for our kids as well, supporting those who have alopecia and also the siblings. So it's a really neat camp and it's, you you have to sign them up through the registration. ~ if you haven't signed them up, just feel free and you've already registered for the conference.

just feel free to email us and we can make sure that they're registered for that. But that is part of the child's registration. I will ask another question here. Let me see, this one came up. As a 17-year-old, would I have the option to go to either kids camp or the session? Yes, you can go to the kid. As 17-year-old, you are able to attend also a session that you feel might interest you.

with your parent as well. There are sessions that probably would interest you, so please feel free to do that as well.

MARY WILLS: (25:42)
I'll also add that's actually relatively common with our older teens that there are fun things they're doing at camp that they don't want to miss, absolutely. But there's also certain sessions that they don't want to miss and that's relatively normal. I see it all the time.

JUDY WILLIAMS: (25:57)
Yes. Thank you, Mary. Here's another question. ~ How can I encourage my child to join a support group if they don't think this is the right space for them?

MARY WILLS: (26:09)
I guess my first question is why don't they think it's the right space for them? I think that it's important to encourage your child to join and you can say, you know, you don't even have to talk about alopecia. It's just meeting other people. I swear for a year we talked about Taylor Swift's tour when that was going on. I feel like another year there was, most of the girls were a little older. So they were talking about applying to college and you know,

If you are not comfortable talking about alopecia yet, that's perfectly fine. ~ We have some girls that go to the support group that only communicate through the chat and we know they're on there. Like I can see them, but they're just not comfortable talking yet and that's okay. So I think just stating, know, it doesn't ever hurt to meet someone new. It doesn't hurt to listen. You know, maybe you have advice that can help this person. You know, I have some kids who they go through very different experiences in the schools compared to other children. So it kind of adds that perspective or other people can give different advice of like, this is what I did to get through that. So I think just being open-minded, let your child lead and just let them know, like there's just no pressure, you know, in the group. Like you can talk as little or as much as you want.

JUDY WILLIAMS: (27:23)
Okay, thank you. And we have several people asking what time is the girls support group on Mondays?

MARY WILLS: (27:30)
So it is 7 p.m. Eastern time because Dr. Kate and I live in Eastern time. So it's the third Monday of every month. We do have people from other time zones who join.

JUDY WILLIAMS: (27:38)
Okay, thank you.

Okay.

And here is another question is, does peer support online like the virtual meetings help as much as in-person connections?

MARY WILLS: (27:54)
So it depends. I may have a biased opinion and say it's good to have a mix of both, but that can come from a lot of different reasons. I have some people in my group that just live in extremely remote areas. They just do not have that opportunity. So I think something is better than nothing. Also Cleveland, where I live,

It's just like hard with traffic to navigate. If you want to live on one side of town, it's hard to get together. So I think virtual just increased access to more people in my own city or even nationwide. But even with that, running a virtual group, I still offer those in-person events. We go to a Cleveland Guardians game every year in September. Even if you're not in the group, like you can go. So MLB does like team up if your city has a baseball team.

And so I offered those, the camp conference, Walk for Alopecia's in my city. So I just try to encourage people to do these in-person things if they're interested, absolutely. There are some people, depending on where they live or what's going on in their life, this is just not, they're not able to do those things. So it's very individual. What works for you works for you. And I don't think there's anything wrong with whatever avenue you choose.

JUDY WILLIAMS: (29:09)
Okay, thank you. And here's another question. If you are okay talking about your personal experience, what was it like for you as a young child with alopecia areata and when did you get involved with NAAF?

MARY WILLS: (29:24)

So I was diagnosed at two years old. My hair was like patchy, alopecia areata all the way through school. And then I went to Universalis at 18 and it really started my senior year of high school, but completely went to like a severe level, maybe the summer in between high school and college. As a child, it just kind of depends like where the patches were and their seasons. So some years it's better than others.

I do remember people asking like, where did your eyebrows go? Or, you know, why do you have a bald spot on top of your head? Everybody has a different personality. I'm a very direct one. So I will just say, I have alopecia areata and that's it. Like that's the end of it. So that's kind of how that was perceived. And then as in adults when it went to more of a severe level, I personally felt that normalizing the experience was most helpful. So, you know, when I was in college, I was in a sorority and, you know, pretty much lived like a normal 20s experience, had a lot of friends, and I think things are as normal as you make it, right? And I think just being comfortable with that, just like, you know, some people wear glasses.

You know, everyone has something. And I think just kind of being honest about that, that there's nothing you did to cause this. It is very difficult to treat and that's not always accessible to everybody. And at the end of the day, you're still a person and you know, every single person is unique and different and should be celebrated for that difference. So I hope that answers your question.

JUDY WILLIAMS: (31:05)
Thank you. Okay. And this is another really good question is how can I tell if my teen is actually coping well versus just not talking about what they're going through?

MARY WILLS: (31:18)
So is your, my question would be, is your teen avoiding things that other teenagers would not avoid? I'm just thinking of playing sports, like are they afraid to put their hair in a ponytail or running their short hair? You know, they're running around and they don't want people to see their spots or are they not doing the sleepovers? Are they disengaging from typical teenage activities? If they're disengaging, then possibly that they are having a difficult time coping. It could be something else that they're going through too. And I think the biggest thing is just keeping that open communication and just letting them know like, you're here to talk about it whenever they're ready or you can link them to the resources to talk about it whenever they're ready and just letting them know that you're here I think is important. A lot of people, they may not be comfortable right away or right now, but I think letting them know that that door is open is what's important.

JUDY WILLIAMS: (32:16)
Okay, and he was kind of a similar question that we've asked, but this is like the way this is worded. The question is, what's the way to bring up support groups with my teen if they are resistant to talking about most things with me?

MARY WILLS: (32:31)
Okay. That's a tough one. And not unusual, right? Like we just know if your child development, teenagers are focused on their friendships, maybe not their relationships with

their family. you know, I think if you're driving them to school or you're driving them to an appointment and it's just that one-on-one time you have with them or you guys are watching TV, just letting them know, hey, there's this support group for teens that I think would be really nice for you to join or could be really helpful to you. You can share, like you've joined an adult support group, just kind of introduce them to the idea. I think privately, on a one-on-one is usually most helpful for kids, especially kids who have siblings. This is difficult to navigate, especially if your siblings don't have it. So I think just that one-on-one time talking about it, I would suspect they're more likely to open up.

JUDY WILLIAMS: (33:26)
Okay, this one is my 15 year old son is about to change schools because of a move. He has universalis. He's been with this group of kids his whole time in school, so I'm really concerned about how to help prepare him or his new classmates for his transition to a new school. What would you recommend?

MARY WILLS: (33:49)
So I have seen a presentation at the conference. This woman who lives in California, she talked about doing like an IEP meeting with the school or educating the school, even if they don't need a full IEP, but educating the school prior to the child enrolling or prior to the child starting about this is this disease. Every school culture is different and every person has a different comfort level. But I have seen parents who

They take the initiative to, I want to educate their class about this. That way there's no questions when the child comes in. Like they've put on a presentation, they've told the teachers. And I can even think in my own life, I remember we had a new student in our class who had autism and I was in probably elementary school and our teacher wrote on the whiteboard, like, what is autism? And we talked about it before he came and joined our class. And that was really helpful to fourth grade Mary. And I think sometimes introducing it first to the teachers and getting their feedback of what they think the school would respond to because they know their students better than we do may be helpful for that support because educating people is just going to give less shocking maybe questions.

JUDY WILLIAMS: (35:05)
OK, and somebody asked about the youth mentor program and I don't know you might be able to answer this and I can too, but you said something about a youth mentor. What does a youth mentor do and would the youth mentor be the same age as my teen? I can help answer that one. As Mary mentioned, the family select the youth mentor and we have all ages ~ from five from the age of sorry from the age of 17 all the way up to the age of 30 who are ready to get a mentee and mentees need to be from the age of five all the way to 17 and you get to select them what age they are. Some select older, some try to stay within the same age group. So you really it's up to you and the mentor is really there to support them. And Mary mentioned something really important. It's not always about just talking about alopecia areata.

You'd be surprised how many mentors have reported in mentees. It's like, I want to talk about something else besides my alopecia areata. But what they love about the mentor program is that they have somebody that truly understands what they're going through. So if they've had a bad day, they would know, you know, what they're feeling. But, you know, sometimes if it's about a sport, there was one mentee that mentioned, you know, they were in baseball and it was so difficult for other players to understand.

He had lost his eyebrows and nobody, none of the other athletes, not the coaches understood how hard it was for him because of the uniform. He couldn't wear, you know, something to protect the sweat from going into his eyes. And it's like, I couldn't speak to anyone about it or somebody to support me in that way. But them having a mentor who was also in baseball and they were able to come up with the plan to be able to talk to the coach based on his experience and how he also spoke to the coach. So it's in many ways, you know, if somebody there who has actually gone through it and can help guide them in a situation and navigate alopecia areata. Here's another question I'll leave to you and how do I respond to people who assume I have cancer or they just flat out ask me why I don't have hair?

MARY WILLS: (37:14)
So it is easiest to navigate your responses when you write them when you're calm. When you write them when you're away from the situation. I've had those assumptions too. And so you're not alone in that, it's a very common one. I mean, I think a lot of it depends on the intent of the person, like the way they're asking things.

So if they're asking in like a kind way out of pure curiosity, I mean, what you're comfortable with is how you'd respond. Some people may say, I'm not comfortable responding to that question right now. And that's okay for you to say. Some people may say, ~ I don't have hair because I have alopecia areata. And then they might ask more questions. You could say, have alopecia areata and I don't have time to explain right now because I'm, you know, writing a paper and I'm in school.

So I think a lot of that depends on really what is the intent of the question, how the question was asked. And I've had the teens, like they write out all of their responses to every scenario, right? And they practice them. That way when they're asked, they're just not put off guard. They're just ready for it. Because that shows that confidence and that preparedness, which I think is important because unfortunately we are gonna get these questions and that is just the reality of situation. Do I wish people did not ask me that all the time? Yeah, absolutely. But I kind of have to navigate my responses and reactions to it as well. So I think practice makes perfect.

JUDY WILLIAMS: (38:42)
Thank you. Here is a long question. I think there's several questions in one, but can you talk about how your teen group has evolved over time? Are there always new people joining? Have you met in person? How many teens are in your group? Can you talk a little bit about that?

MARY WILLS: (39:01)
So I think I have been doing this group for probably five years is my guess. So our group has evolved because some of the girls have just graduated. They've turned 18 and once you're 18, you're not part of the teens girls group anymore. You know, we only have the group for

12 to 17. So I'd love one day to have like a young adult group or a volunteer to facilitate that. So I would say, yeah, our group dynamics have evolved because our girls grew up and I have met a lot of them at the conference. I would say that is actually where I met any of them. And I've had like the parents before the child joined call me just to talk about it. You know, that's understandable. And it kind of depends on the year because we would have some years where we just have like younger, you know, girls and some like the more older. And when it comes to attendance, honestly, it just depends. Like we might have a group that's like really strong attendance, but it's okay that someone decides they don't want to do the group anymore because that means that they no longer need the support. So it's not always a bad thing if someone's like, you know what, I did this for a year and now I'm kind of like ready to disengage from the group because I'm going to focus on soccer or something else. And they can always come back as long as they're under 18 years old. So.

JUDY WILLIAMS: (40:22)
Okay, great. This one is this question is going back to what you were talking about preparing your responses is how do they practice the responses? Do your support group members to your teams you get to do this during the support group or during your regular support meeting? Do you encourage them to practice with family or friends?

MARY WILLS: (40:42)
So it's whatever you're comfortable with and everyone practices things differently because every person learns differently. We have in the group in the past, they were practicing them together as a group. This is what I want to say, you know, when I'm asked this way or this time and they can do it that way or I've had some people, they just sat down and wrote all the different questions that they have been asked or anticipate being asked and they wrote it down and they practice with themselves in a mirror.

But if there's somebody who would feel more support and more confident practicing in front of their friends or family, I think that's appropriate too. Everybody's different. I know for me, I'd rather practice by myself, but I'm a different person.

JUDY WILLIAMS: (41:24)
Great, thank you. And speaking of support groups.

Somebody just ask, are there any groups out there to help adults with this disease? And along with that, there's another question about, should I also join a support group as a parent if my son joins a support group for teens? is it important to do that? What are your thoughts on this?

MARY WILLS: (41:50)
So we have the teens groups and then like the regular support groups. I can speak for mine as adults and I think a lot of them are typically adults. I do have parents who join their local support group while their kid is in the teen group. So that is pretty normal. In my Cleveland group, which is for adults, I've had parents join and they had their child also, you know, debut on screen and say hi, know, especially depending on the age of the kid, how involved they're gonna be. So when it comes to joining a support group, it's just to listen to other people's experiences. Maybe you have wisdom and advice, or maybe you have questions

too. Support groups are usually not hurtful, and you know, you can try it, and if it's not for you, it's not for you, but I'd always encourage somebody, you know, just to give it a chance.

And there's different online groups. So if there's one group that you just don't feel like is the best fit, you can always try a different one.

JUDY WILLIAMS: (42:45)
Thank you. And where can my team learn more about wigs without being overwhelmed?

MARY WILLS: (42:53)
So with the internet, is overwhelming. And social media, and I didn't experience, like when I was younger, we didn't have like Instagram and all this stuff like we do today. So usually in cities, they will have like a wig store or somebody like a cosmetologist who specializes in that for any medical diagnosis. So it could be helpful that they just do their first wig experience in person with somebody who helped them navigate there are different brands. There are different cap constructions. There's different feels, I guess I would say, different colors and things that you're looking for. So I feel that usually people feel comfortable when they go into like a store that specializes in this. And then once they get a feel for what they like, ordering online is usually a little cheaper. But.

I think that might be a good place to go. I mean, you can always check reviews online. There's a lot of, you know, websites and Instagram, local wig makers and all these things. I think it's really just taking it like one step at a time and knowing that you don't have to commit and you don't have to feel pressured to commit to something.

JUDY WILLIAMS: (44:04)
Great, thank you. I'd to add, please look on our NAAF website. We do have a new confidence guide that has a lot of great information about wigs as well as other support for wigs. And then we have past webinars as well that you can watch that are on our website. We do have somebody asking about

Oh, it's about the youth mentor program, how we can get as an adult, how we can get involved on our NAAF website. We do have youth mentors again up to the age of 30 where you can sign up and apply to be a mentor for a child or a teen. Our applications online, as Mary mentioned, there is a vetting process, but please feel free to look on our website to be part of this program.

One of our other questions that came up, what is your experience from your support groups with teens? What do you think would, what would you say has been the most positive thing that others have mentioned was important for them as a support group? I don't, I'm assuming it's because it's, what would you say they've benefited out of this program. Like if you've talked to some of the girls you've mentioned after they're 18, they don't want to leave this group. Why would you not want them? Why do they usually decide not to leave? mean, have they made friends besides that? How has it made an impact in their life from what you've heard from these attendees?

MARY WILLS: (45:41)

think one, it normalizes the experience that you're not the only person with this. So they build that connection. And I think that's really helpful. I think another thing with my colleague, she's a physician. So a lot of the girls are like, wow, you're a doctor. And that's really powerful, I think, for them to see that we can still achieve things. We can still do things that everyone else does, right?

13 girls, so they're gonna ask like, you do you have a husband or a boyfriend and all those things. And I think it's important to let them know like, yeah, you can live a very normal life and you can still do everything you've ever wanted to do. And I think that's important to a of the girls just to see like, you know, you can be happy, you know, despite having this and we can navigate this challenge and.

I think a lot of it is just the connection. They find out that they all like the same bands and they're all in some sort of after-school activity and they just realize, wow, this, you know, I'm from like a cornfield, Ohio originally, and there's other people in California, they're just like me, right? Like my kids may feel like, wow, this person lives in the other side of the country, has the same goals, dreams and desires that I have. And I think that's...really important for the kids to see.

JUDY WILLIAMS: (47:04)
Okay, great. Thank you. ~ And then one final question that just came through is, it easier for boys dealing with alopecia areata?

MARY WILLS: (47:14)
So I say, no, everyone's different, right? Like I've met some women who this does not affect their life at all. I've met some women who really struggle and I've seen it with males too. I've seen male adults like really struggle and I've seen, you know, some male kids be perfectly fine. I think it's a very individual thing. Like there's only one you and only you are going through it. Even if, you know, your family has it or your friends have it.

It's a very personal experience because you're just one body.

JUDY WILLIAMS: (47:47)
Great. Thank you, Mary. That's all of our questions. I'm going to start sharing my screen. We truly appreciate what you've shared with us today and your experience and the importance of these peer support with this age group.

And I think you can see my screen now. And if you'd like to hear more from Mary Wills, come and hear her speak in person at the annual NAAF conference. NAAF's 41st annual conference will take place in Orlando, Florida this year from June 25th to June 28th. The conference is the largest gathering of the alopecia aerate community in the world, and you are invited. It's a unique opportunity to hear directly from experts like Mary, connect with the community leaders in alopecia aerate and meet others who share similar experiences. So register today. And thank you again to Mary for being our webinar speaker this evening. To our audience, thank you for joining us and please share your feedback on today's webinar and help us plan for future presentations. A link to a short survey will pop up in your browser window at the end of the webinar. Your feedback is appreciated.

And join us for our next webinar, A Different Kind of Support, How NAAF's Annual Conference Helps People Learn, Connect, and Advocate. This live webinar will take place on Wednesday, May 13th, and join us for an open and honest conversation designed for individuals and families who are new to NAAF or exploring whether conference is the right fit. Hear directly from community members living with alopecia areata as they share what they were hoping to find at conference, what surprised them, and the support that has stayed with them long after. This webinar offers real stories, meaningful insight, and a chance to discover whether conference could be a valuable resource for you and your family. Registration for this webinar is now open. And NAAF support groups are free, and they are led by those living with alopecia areata or their parents who understand the alopecia areata experience.

These groups are designed to provide a safe welcoming space where people can share, listen, and feel understood. Each group allows participants to connect with others who truly get it, share experiences, ask questions, and build community at any stage of their alopecia areata journey. If you or someone you support is looking for connection, encouragement, or simply a place to not feel alone, our support groups are a great place to start.

You can scan the barcode to learn more about upcoming support group meetings. And as Mary mentioned, you can look through our events page and you'll see all of the new meetings that are coming up. And if there's one that you don't really feel, you don't like it, you can feel free to join the other one and it doesn't matter where you're located. A lot of these are virtual and you're free to join.

And we encourage you to stay in regular touch with NAAF. Use our QR code here to subscribe to our email list for regular updates on alopecia aerate news and research, the monthly NAAF electronic newsletter, and notices about upcoming webinars and other programs. To learn more about NAAF and the resources we offer, please visit NAAF.org or email us at support at NAAF.org. And this concludes today's webinar program.

Thank you again for joining us, Mary. Thank you for doing what you do, ~ everything you do for NAAF and the alopecia aerate community. And thank you for joining us this evening. We look forward to seeing you on the next webinar.