



NAAF WEBINAR

A Different Kind of Support: The NAAF Annual Conference

May 13, 2026

JUDY WILLIAMS: (00:00)

Welcome to the National Alopecia Areata Foundation's webinar, A Different Kind of Support, How NAAF's Annual Conference Helps People Learn, Connect, and Advocate. Joining us today is Sabin Heeman, Claire Shelton, and Ruth Rama-Witt. And I'm Judy Williams, Director of Community Support for NAAF.

This webinar is part of NAAF's You Are Not Alone education and empowerment webinar series. NAAF gratefully acknowledges the support provided for this webinar series by our partners, Lilly, Pfizer, and Sun Pharma.

Before we get started, I'd 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 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 supporter, please visit our website at NAF.org.

And we know that it can be confusing to hear all 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, a different kind of support: how NAAF's annual conference helps people learn, connect, and advocate. But before we dive into our panel conversation, I want to take a moment to step back and talk about the NAAF annual conference and why it exists. At NAAF, we support people affected by alopecia areata and their families in many different ways through support groups, peer connections, educational resources, and youth programs.

The annual conference is just one of those resources, but it's a really special one because it brings so many of those supports together in one place. The conference is designed to be a space where people can learn, connect, and advocate, whether that means learning about the latest research and treatment options, connecting with others who truly understand life with alopecia, or gaining the confidence and language to advocate for themselves, their children, or their families.

What makes the conference unique is that it supports people at different stages of their alopecia journey. You'll find not only those living with alopecia areata attendees, their parents, siblings, grandparents, and other extended family attend. Some long-time attendees and first timers are all in the same space, each coming with different needs and walking away with different takeaways. So through this webinar, we want to show how the conference isn't just an event.

It's an extension of NAAF's ongoing support. We'll be hearing from these amazing three panelists who each engaged with the conference in very different ways and together they'll help tell a fuller story of how their resource or this particular resource shows up for our community. So we're honored to have these panelists joining us today, Sabine and of course Ruth and Claire.

I will introduce Claire first so we can ask her a few questions. Just a short introduction, Claire is a current third year law student at the University of Houston Law and will graduate in May. She will be working as an attorney in Houston, Texas at a firm focused on health law. Claire was diagnosed with alopecia areata in third grade and experienced complete hair loss during college.

During that time, she became involved with the National Alopecia Areata Foundation and attended the NAAF conference in 2022. Since then, she has served as a support group leader, a legislative liaison, contributed to various events and panels, and currently serves as a walk site leader for Houston.

Ruth is our other panelist, and she is a Manhattan-based executive recruiter specializing in C-suite and corporate infrastructure searches. Her daughter Bailey was diagnosed with alopecia areata at age two and NAAF became Ruth's primary source of support and education during their family's journey navigating the condition. After attending her first conference in 2011, Ruth became a dedicated advocate and supporter of the organization. She joined the NAAF board of directors in 2024 and was elected as the board secretary in 2025.

And we have Sabine.

who is 18 year old from Los Angeles and has just completed her freshman year at Purdue University, where she's pursuing engineering. Sabine has been living with Alopecia universalis since the age of nine and has been attending the NAAF conference since 2017. Over the years, she has loved growing up through every age group in the conference's youth camp programs. And now entering a new chapter, Sabine is especially excited to attend her first conference as an adult.

and continuing building those connections with the Alapisha community that has meant so much to her throughout her journey. So thank you, all three of course, for joining us today,

And I'll let Claire tell us a little bit about yourself, your journey, when you were diagnosed and how you came about to joining us at the conference.

CLAIRE SHELTON: (05:58)

Hi everyone. Thank you for being here. It's so exciting. Please come to conference. It is so fun. so, like Judy had said, I actually graduate law school in like four days, which is pretty crazy. have, so I do have hair.

I have alopecia areata. Right now I have hair because I'm getting treatment. I lost all of my hair in college. I was diagnosed in third grade, but I lost all. It progressed to almost universalist. I wasn't quite universalist, but I was close. In college, I wore wigs. I had to do eyebrow tattoos. I never did eyelashes because I wasn't very good at it, but I know that I could have tried if I wanted to.

Let's see. I started to get involved with NAAF my senior year of college. I wanted a community and there wasn't an active support group in Texas at the time. There were other support group leaders that had since kind of retired out of support group leading that I had connected with through Judy, who is also fabulous. So that was my first kind of break into NAAF was 2022. I was a senior. So I didn't grow up with NAAF.

I led a support group for a few months before attending conference for the first time in June. and the rest is history. I've loved NAAF. I've been involved with NAAF since. it's a fabulous organization. So.

JUDY WILLIAMS: (07:34)

Wonderful thank you Claire. So was there a moment, a session or a conversation at conference where something really clicked for you?

CLAIRE SHELTON: (07:47)

Yeah, I had, I am an extroverted person, but was I stoked that I had lost my hair? No. I socially felt stunted and that I had this missing piece of people who understood what I was going through. And conference gives that to people. The first night of conference, I went with my mom and that was really nice too, cause she's kind of my backbone. had her with me.

and I was an adult. I didn't do the kid program. So it me and my mom walking around with all these adults and try to figure out what's going on. but the moment that I was like, wow, this is kind of the most incredible thing I've ever seen. And I've never felt like there's such community ever. my mom and I, with our suitcases, we had to fly in because we're from Texas. We walk into the hotel and it is a sea of bald heads, just an absolute sea of bald heads. We were looking around like,

my gosh, this is so cool. Like there were hundreds of people in this hotel lobby, just like wanting to support each other and love on each other. And I thought that was really special. So that was a moment where it kind of clicked like, there are a lot of people who rely on each other here at conference. And it was really, it was really fabulous. So.

JUDY WILLIAMS: (09:05)

Great, thank you, Claire. And how did having access to experts like research updates or peer discussions really impact your confidence as a patient with alopecia areata?

CLAIRE SHELTON: (09:17)

Yeah, it's a great question. Confidence in alopecia is hard. I lost my hair at a time in my life. I wasn't in high school, which is maybe a bonus, but I was in college. And that's definitely a growing time in your life where you're trying to find yourself and figure yourself out. I didn't have the confidence in my disease that I had wished that I had had at the time.

However, I had decided that I was going to go to this conference with as open of a mind as possible, see what was out there, see the kind of community that was out there, and see the kind of support that I could have. And I went to conference and I learned so much about my disease, about the community, about the different psychosocial impacts. That was one of my buzzwords that I learned at conference. Like you learn, you are able to put into words after hearing so many different people talk about your disease, all the things that you had been thinking that you didn't have the right words for yet. Like that kind of changed the game for me. Plus I learned about JAK inhibitors at conference and that obviously changed the game for me as well. So 2022, I keep saying 2022 because that is the year they were FDA approved, just for context. So when you go to conference, you're learning about the most up-to-date treatments that are you're learning from the experts of the experts these are the creme de la creme of people who are involved in NAAF research and outreach you are getting Every amazing expert that you could possibly ask for I mean it's more information than my mom and I even know knew what to do with But I did learn about JAK inhibitors. I took that information with me, because I felt more confident, back to my dermatologist and said I want to try this I heard from these doctors that are doing these amazing things

Let's do it. I think I can handle it. And we did. And I have been on them since and it worked for me. So conference gave me a lot. It gave me a lot and I'm very thankful for

JUDY WILLIAMS: (11:22)

Great. Thank you, Claire. It's great to hear how you found it so empowering to go to conference. And you mentioned confidence. And you said you had your mom there supporting you as your backbone. So what would you say to someone who feels unsure or intimidated about attending their first conference? Perhaps there may be someone who doesn't have somebody that they can attend with. What would you say to them?

CLAIRE SHELTON: (11:51)

I mean, I think, and my mom and I, after the first night, we had separated. We did our own things. Because my mom was interested in different stuff than I was. She wanted to know more about the parent side of it. It's like, how do you deal with kids? And then I wanted to know more about like, well, I want to be, I don't want to hear about the parents. I want to hear about myself. So I went to different stuff. You know, it's a conference. There's different events going on at different times. So we were able to split. I relied on my mom that first night, but after that, you flourish. I mean, there's so many

people there that are just like you, you know, who are going through the same things that you were going through and they make you feel so comfortable. So I think that the confidence for me came with being able to see people that looked like me, talked like me, thought like me and one of the same things that I did out of my alopecia, you know, I

wanted treatment and other people there did too. So it was nice to be able to talk to people who completely understood what I was going through. And it gave me the confidence to go back and tell the rest of my family, my dad and my brother, how I was feeling, my friends, even professors. I felt so much more able to come into myself. All that to say, long-winded, one thing I would say to someone who is nervous, the people there will make you feel comfortable. It is an inevitability. They are the warmest people. So.

That is my two cents on.

JUDY WILLIAMS: (13:20)

Well, I love that you mentioned that your mom kind of went on her own way and found the support for parents because we have Ruth, her experience as a parent of a child with alopecia and how the conference impacted you. So thank you, Claire. But before we get started, Ruth, you want to tell a little bit about your story, your journey with your daughter?

RUTH RAMA-WITT: (13:43)

Sure. So Bailey is my daughter. She's now 19 years old. She just finished her first year at universities and she just came home three days ago. We brought her back. She was diagnosed with alopecia areata in 2009. We had just moved to LA actually Sabine. We were there for my husband's work so everything was new. We didn't know what was happening. And in 2009 there really wasn't a lot out there about alopecia areata. There just wasn't information. No treatment, no treatment. It was tough. I prayed that it was ringworm. We brought it to the pediatrician. The pediatrician poo-pooed it, gave us a tube of steroids. It was really a tough time for me as a parent, not knowing what this was. Her hair rapidly started to fall out and

No one could really help us. My first conference was in 2011, also in Los Angeles. It was at the Century City Plaza Hotel and I was so excited to be there. I knew that experts and scientists were gonna be there. And as a matter of fact, the first doctor who treated Bailey, Dr. Richard Strick was part of the Scientific Advisory Board for NAAF.

So that was my first NAAF conference. My involvement with NAAF, know, a lot of this is my sense of gratitude. I had found NAAF midnight, one night, Googling, you know, trying to find information on the internet. And I saw, you know, the phone number, called them the next day. A woman named Laura answered the phone on the first ring and sent me a folder with ditto sheets. I don't know if I'm dating myself, but photocopied information and brochures on what this disease was and a list of phone numbers and support groups. That was all I had in 2011. And I'll never forget it. And that's why I will also do anything and everything for this organization that has been with, has been there for me, now for my daughter and my whole family since the beginning.

JUDY WILLIAMS: (16:01)

Thank you, Ruth. And we know you do and we appreciate it. So what were your biggest questions or concerns as a parent before attending the conference?

RUTH RAMA-WITT: (16:13)

Well, I was excited to go. I was. I mean, it was a little nerve racking, but for the most part, I was excited to go because one, this was it. I was going to find my people. And I went alone. It was actually the day of Bailey's preschool graduation. And I left early so I could make it in time to the conference. I was looking forward to just being in the world of other people with alopecia areata. I didn't know what to expect.

I didn't know that there were gonna be parents. The camp, my timing was I arrived at the hotel and there was a whole line of little kids with bald heads and I was both moved and emotional and yet at the same time it was like, wow, it's not just my daughter. So as far as what I was expecting, I was just open to it. I knew that there were...doctors and scientists, but I knew that there were also a lot of support groups. And for me, it was just to find my people.

JUDY WILLIAMS: (17:18)

Okay. How did you feel that the conference supported you as a parent, not just your child?

RUTH RAMA-WITT: (17:25)

As a parent, I made new friends. I made what I call my alopecia areata mom friends, who to this day continue to be my friends. And we stay in touch. Our children have grown up together. I think one of them is now also very involved with NAAF, Harrison Goldberg. My other mom friend, Melody, her daughter, Kaylee, is the same age as Bailey. And I think we've sort of...

walked a parallel path of the ups and downs of alopecia areata, including looking at treatment and pursuing it. That's the most important thing that I got from the conference for myself.

JUDY WILLIAMS: (18:07)

Great. And so how did connecting with the other parents impact how you show up for your child at home?

RUTH RAMA-WITT: (18:17)

You know, like I said earlier tonight, different phases of your child's life will also bring different reactions or ways of dealing with alopecia areata. When you have other parents going through what your kid is going through in that same life stage or age, it gives you insight. What are some of the ways that you can talk to your child or not talk about it?

How do we talk about treatment or not not having treatment? Peer pressure or how are you dealing with this in school? I found that through parents and that to me was what really resonated and what I turned to time and time again through the best of times and through the worst of times.

JUDY WILLIAMS: (19:05)

great and I love how you mentioned you know how you got your alopecia moms and your friends and we know that even at conference now that some of them their children have now grown up moved out there still are parents who attend the conference without their children and they're still there supporting other children and and you know still seeing their

friends who have now become like part of a family have you seen other some of your friends that are still there like Harrison Goldberg and his parents.

RUTH RAMA-WITT: (19:36)

Yes, I think that there's one family in particular where they had been going there for, I mean, their son is now in his 30s and they had been going there since he was seven or eight where the conference became part of their summer plans, summer vacation plans. And it's a circle of five or six different families whose kids have grown up together. This is their thing. This is their trip. And I see them every year and now it's just the parents.

So it's wonderful. really, for that one time each year to be part of this community where you can feel safe and your other parents get it, they get you, you just look at them eye to eye and they get it. And there are painful moments. There are, you know, sessions that only another parent with a child with this condition can understand. And for me, that is the special time of the conference.

JUDY WILLIAMS: (20:33)

Thank you, Ruth, for sharing that. Now I'll move on to Sabine, who can give us her perspective on how the conferences impacted her. I know you started there as a child, so I'll let you tell us a little bit about your journey with Alopecia and how you got involved with the conference.

SABINE HEMANN: (20:54)

Yeah, so my name is Sabine. I'm from LA as Ruth alluded to and I was diagnosed at the age of eight and my hair fell out at the age of nine and has stayed that way ever since. Although I am on treatment and I am responding just a little. I'm a little bit fluffy. And so when I was starting out with losing all my hair, it was very fast, only a couple weeks. And so

While my parents were trying to figure this all out with me, NAAF was our go-to resource. They helped set us up with how it works, what the existing treatments are, and all that sort of thing. And so we actually planned to go to the conference that year, but we ended up having to go when I was 10 because we had plans that year.

And ever since, we've been going to conferences wherever we can. I became a legislative mentor back when they were called that. Now they're teen advocates, but the mission is the same, to work with the same kind of legislative advocacy that NAAF does on Hill days. I've since aged out of that program. I'm now a legislative liaison. And I've been doing that for seven years. So I've been...

really involved with advocacy and even though I'm in college now and it's a little harder for me to get on these calls and kind of share my story with like the House of Representatives and the Senate, I still love getting on these opportunities when I can.

JUDY WILLIAMS: (22:39)

Thank you, Sabine. So tell us, what do you remember about attending the conference or youth camp as a child?

SABINE HEMANN:: (22:47)

So as a child, I started in the tween camp and moved up into the teen camp. And what I found there was that the atmosphere is so different from any sort of like transient front group that I've had at school or in another summer camp. We are very helpful by default. We all understand each other from the outset. And so when we're playing or when we're sharing stories, we're always

We're always together in that sense. We're, we find it easier to share our stories because we know that at least somebody in that room is going to understand you completely. And so even when we're sitting around playing a card game, it is so easy to just slip into these really meaningful discussions about what it's like to live with this condition. and I find that the quietest kids, by the end they've been brought up with the rest of us and are laughing along with us, are feeling free enough to be able to have fun at kids camp.

JUDY WILLIAMS: (23:57)

Great, so how did being surrounded by all the other kids and teens with alopecia shape your sense of self?

SABINE HEMANN: (24:07)

it really helped me to see my own birth as a friend and advocate, because we don't necessarily stay in our little island of kid tween teen. over time, we've had more and more of these sessions where teens will talk to tweens or talk to the little kids. And even though the stated purpose is us helping them, I find that it's really nice to take notes from the little kids on how to embrace having a body that might look different from what you expect out of a teenager. And so even though we have the makeup stuff outside of kids camp and learning to treat yourself right from the perspective of an adult, it's also really important as a tween and teen to have this kind of little kids perspective of, hey, doesn't really matter what we are as long as we can have fun and as long as it doesn't interfere with our kind of ability to view the world and understand it and befriend it.

JUDY WILLIAMS: (25:22)

Okay, and you mentioned that you started in the tween camp. So as you got older, how did the conference can continue to show up for you? I'm sure in different ways.

SABINE HEMANN: (25:35)

So for me, the conference introduced me to lifestyle choices, public speaking, medical advancements, stuff outside the realm of kids camp that got brought in. I've had the pleasure of speaking on several impromptu panels, one of which is on the medical treatments and how that works and our journeys through it. And that has helped me kind of figure out how to do that elsewhere in my life. But especially it's kind of fed back into the kids camp community and enabled others to come up and speak with me. in some cases, I'm not on the panel. Sometimes it's younger kids who have gone here before and observed what it's like to be able to help out. And so they are doing what I used to do two, three, four years ago.

and find that really cool.

JUDY WILLIAMS: (26:36)

Okay, and you also mentioned, you started doing a lot of advocating not only for yourself but for others. How would you say that these early experiences, you know, at Kids Camp and the conference, how did it influence how you advocate for yourself today?

SABINE HEMANN: (26:53)

I found that I've learned how to explain kind of myself and my story, who I am. And I've done it hundreds of times now through conference calls with legislators, through panels at the conference, through things like this, through the kids camp. And so that has made me, I feel a better speaker and kind of a better person because I can be right there and help untangle somebody else's feelings.

Um, and in terms of my self-advocacy, um, I'm able to choose how I want to explain myself. And that can go a long ways towards like protecting my peace or clarifying that, um, I'm not the person they think I am. So it's really helped me assert that I am my own person and this is how I see myself.

JUDY WILLIAMS: (27:53)

Great, thank you Sabine for sharing that. how did you end up coming to the conference in the first place? What is it that pushed you or motivated you to attend your first conference?

RUTH RAMA-WITT: (28:08)

I just wanted to know what was out there. What was the research? Who are these doctors? What is this? How can I meet people who have experienced this? I mean, again, this was 2011. was like, there was nothing. I just wanted to find more information. You know what they say about moms? When we want something for our kid, nothing's gonna stop us. I'm sure Claire knows that too. That was it. That was it.

I mean, I left preschool graduation so I could get to this conference.

JUDY WILLIAMS: (28:44)

Thank you, Ruth.

CLAIRE SHELTON: (28:47)

say that I had kind of a similar experience. My mom and I both were like, you know what, there's got to be more. At the time, I had just switched dermatologists and that also completely changed the game for me. The dermatologist that I had that actually put me on Jack inhibitors after I had talked to her about it was very different than what I had had before.

I was just learning things about like what I even had, like what disease I had, what even is going on. For years I was just getting steroid shots. I would go into an office once a month, get steroid shots and then leave. And I'm like, what am I doing? What am I doing? I don't know anything. This is painful. I'm unhappy. There's gotta be something else. And my mom and I found NAAF and then conference like right after. So we were like, we're gonna learn more. There has to be more. And there was a lot more and that was really cool.

RUTH RAMA-WITT: (29:42)

have to just chime in with Claire that that's the other thing. It's that sense of empowerment, right? Because you're getting the information, you're feeling connected to a bigger community, and you're making friendships that will probably last for life. It's this special little place in your life where parents just know what the other parents are going through. Young people know what their peers are going through. It's really special.

JUDY WILLIAMS: (30:13)

Great, thank you. And what do you think being in the same space, even just once a year, why it matters so much after being at conference?

SABINE HEMANN: (30:27)

So I find that there's not only kids, like this also applies to adults. I've just happened to see more kids doing this. There's a lot of folks who have worn a wig the entire time they've had alopecia or worn a hat over it. And for these three or four days a year, it's the only time where they feel confident enough to take it all off.

And so it's kind of like they're four days of freedom. here, here everybody looks like you and is willing to accept you and willing to talk to you about your experience. And so even if you're comfortable with wearing a wig or a hat, you know, this is that kind of push that a lot of people need to get out of their comfort zones. And every single time I see folks.

who it is their first time being out in public at all without some sort of covering.

JUDY WILLIAMS: (31:31)

Thank you, Sabine.

once you attended your first conference, why would you continue going? Why did you go to your second conference? Like if you found that support, that community, what was your drive? Why have you continued attending?

RUTH RAMA-WITT: (31:51)

Well, for me, it's one time or a couple of times it was with my daughter Bailey. The most recent one was last summer. We were in Chicago. It was like a mom, mom and daughter trip that we just had such a great time. Another time it was as a family. So with her dad, it changes every year, right? The dynamic, the need where we are mentally with the condition as a family, also as a young person.

For me, it's always been that community and going back to that community. And look, my daughter has a full head of hair, know, sometimes maybe she may not come with me to every conference, but for me, reinvigorates my desire to give back to this organization. And I don't know, it's just something that makes me feel like this is a community that I want to continue to support. I'm a part of this community.

It's given me so much and of course helping other people too, because there are people who, like Sabine mentioned, they've worn wigs, they come to the conference and it's an emotionally moving time and I also want to be there for those people.

SABINE HEMANN: (33:05)

And for me, I have to agree with Ruth there on basically everything. And I'd also like to add, you know, the research changes every single time you're making such crazy advancements in this field. When I lost my hair, I basically had two options, which were steroid shots like the ones Claire got and minoxidil, which had already failed me once and I didn't see a point in trying it again. So.

As we've gone to these conferences for the past like 10 years and seen what's been out there, it's always changing every single conference and there's always new experts who can walk us through it in a way that makes you feel like a biologist and makes you feel like you understand it. And my mom says like for parents that is really powerful, feeling like you know what your kid is going through and being able to act on it.

So I have been on two different treatments and now I'm my third. And the reason we keep finding these and finding the confidence to go further and look for another answer to this problem is because we keep going to the conferences and we see a new avenue and we're motivated to go down it.

JUDY WILLIAMS: (34:29)

Great. Thank you, Sabine. And were there forms of support you didn't expect to find at conference but ended up meaning a lot to you?

CLAIRE SHELTON: (34:41)

Yes, definitely. My mom and I went to conference wanting more information about alopecia areata. We thought it was going to be like your state. Like honestly, we had no idea the kinds of like community stuff that happens at conference. We really didn't know. We were like, it'll probably be kind of like a dermatology conference. Like we'll just learn about.

speaker-3 (34:59)

Not true.

CLAIRE SHELTON: (35:00)

Simply not what happens there. Like there are so many support groups and there's like fun stuff you do. There's like dance party night. It's really fun. Um, like it's fun for people. I can see how it would be really really fun for kids and fun as a parent to see your kid like engage in it. It felt like a wedding. Like you see all these different kinds of people, a wedding of bald people. You see all these different kinds of people embracing themselves fully. Multigenerational. It's really beautiful and it's very powerful.

It's such a community builder. I have only been able to go one time because I've been a student for a really long time now, but and I'm taking the bar this summer so I cannot go this summer, but as I get older I do plan to keep going even if I have my hair forever. It's just it's a very moving event and NAP is an amazing organization.

JUDY WILLIAMS: (35:51)

Anything anybody wants to add?

RUTH RAMA-WITT: (35:55)

For me, the most recent one I attended the Chicago one. I mean, there you just feel like there's not enough time. You feel like I'm going to do this. I to do that. But one of the cool surprises I had and I actually felt emotional in this particular session was the young adults panel. They were like, and I think Judy, you're the one who who moderated the 20 young adults who are so

accomplished so phenomenal articulate, I mean I felt so emotional and I was surprised that I felt that way because I thought I'm just gonna listen to a bunch of young people, but it was So moving to see young people doing great things doing great work and not letting this disease get in the way of their lives and For me to see that. I mean, I was in tears. It was it was incredible and it was a surprise

SABINE HEMANN: (36:54)

was actually on one of these panels, one of the first, think, if not the first, and I did see people like crying in the crowd. was mainly parents who were really, who had young children and were really worried about how the trajectory of their lives would go. Because, you know, as a parent, you prepare and you study up and you look at what an quote unquote normal teenagers life is going to look like. And you kind of psych yourself up for that. My parents did too. And then you come to this conference because that whole concept of quote unquote normal teenagers was kind of erased. And so you feel like you have to start over and you don't really know how to build back this idea of how being a teenager is gonna go for your kid. So I was really happy that I was able to kind of clear that up for people and reassure them that their kid is going to have a really fulfilling life, know, hair or not. And I think the kids camp is also really subversive in its expectations for a lot of parents.

because I remember the first time I went and I actually wasn't too into it because I was like, you know, this is just daycare. Like you're chopping off your, you know, 11 year old kid and then you're going to go watch like five dermatology seminars in a row. That's not what it is. And I found it really impactful because I got to talk to folks my age group instead of kind of having to look up and be like,

Hello, adult with alopecia. What was your experience when you were a kid if you even remember that? So that is one of the most surprising things I think a parent can kind of run into is their kid coming home from kids camp at like eight o'clock because they wanted to stay till closing and being like, you know, I learned so much about alopecia today.

JUDY WILLIAMS: (39:12)

Why did you think that having a space like a youth camp mattered so much? What was so important, especially something age appropriate? Sabine, can you talk a little bit about that, how some of the siblings are also part of these camps?

SABINE HEMANN: (39:30)

Yeah, and I do love that feature because it allows the entire family to kind of experience what's been going on. And we experience everything firsthand. And I'm an only child, so I don't have any siblings to tag along. But I do know from seeing it that A, it brings them closer to their sibling with alopecia, and B, it helps them realize

you know, what they've been potentially defending their sibling against. Because the world out there is rough, especially for middle schoolers and high schoolers. And to have a sibling to lean on and to understand your condition and to kind of grow up through that trajectory of your life with you can be really, really helpful and impactful. It's why we have youth mentorship programs, but...sibling is already so close to you and so having that is really really helpful for these guys.

JUDY WILLIAMS: (40:36)

The first one is, how do I get over my fear of going to conference and not knowing anyone? I hate the thought of having to eat meals alone.

RUTH RAMA-WITT: (40:49)

Ruth. I have the official answer, let's say, because I'm part of the kitchen cabinet that helps plan the conference. So first, as a first timer, we're going to call you a VIP and you're going to get a VIP ribbon, because it's very important for us to bring in the newbies, know, new participants, because that is how we grow our community and we meet the needs of the community. So you're going to get a VIP ribbon.

You're also going to get an ambassador who is going to be scheduled to meet you, to greet you when you arrive. We even have a webinar that I've been in where we talk about what to expect. What kind of clothes should you bring? What's the dress code? Bring a sweater because some of the conference rooms are going to be too cold. Bring something festive for the dance party.

You're gonna get that kind of support and guidance, that buddy system from day one because we know you are a new participant or a new, you're a newbie. That's one. At the conference, we will also have folks who are designated to provide you with support because we do have experience with participants who

might be intimidated or afraid and they stay in their room. We have therapists and we also in the past have had rooms or areas where conference attendees can go and have a moment or talk to someone. So it'll be okay because we will support you.

JUDY WILLIAMS: (42:36)

Thank you, Ruth.

CLAIRE SHELTON: (42:38)

I did have my mom on the first day, but once you are in, you're in, you... We have had as human beings without alopecia so many times where we've had to walk into a room and be like, okay, you're... Every first day of school ever feels like that, except you're walking into somewhere where you know that there will be people like you.

Either you're a parent or you have alopecia yourself, you're walking into that room knowing that you will be able to talk to someone who you can relate to on some level because this is a connector, you know? So from there, you'll be fine. It's like first day of school, but like a little easier. You know, like there's a connector, you know? There's something to talk about

with people. So you will be totally fine. And you know what? If you have to eat one meal by yourself, no one will ever know you did it. No one will know.

It is completely personal. You make the conference however comfortable it is for you. know, you can pick and choose. It's a buffet of options for you to come into. You will be fine. You'll make at least one friend.

RUTH RAMA-WITT: (43:48)

I think also to add to, to add to Claire, it's we all are going there with, with certain idea. We were paying money to go there. Let's let you know, realistically. And we all have different goals or we all want to either meet or gain information. It's not. We were going there with a shared goal, which is either to connect, to learn information. So everyone kind of has this.

vibe where they just want to talk to you they want to connect with you whether you're standing in line for breakfast or you're you're checking in at registration or you're at the dance party waiting for your ice cream cone people want to talk to you and there's just that sense of openness and and this this attitude of hey what's your name why are you here do you have alopecia does your kid have alopecia it's it's a real energy

that's in the room for those three days that you're there. It's really special, honestly.

JUDY WILLIAMS: (44:52)

Thank you. Does the conference address kids whose parent has alopecia areata? We do have a lot of attendees who it's the parent who has alopecia areata, actually have, we've heard of a story from one of our community members that she always wears wig and that she finally stopped wearing a wig from her first conference when she stepped into the hotel room with her son. And her son just saw all these people with, you know, no wigs, just kind of like what Sabine said, where you can just be yourself, you know, for the first time, just be free. And he turned around and told her, these are your people.

Like take off your wig or you can take off your wig. And from that moment on, she never once again wore her wig because that gave her the confidence, you know, hearing her son say that to her. we do have sessions at kids camp that talk about and discuss, know, what is alopecia areata. And I think it drives a lot, obviously for that empathy and understanding and then seeing all these other kids.

but we certainly do have parents there who bring their children. It's the parents who have alopecia areata.

SABINE HEMANN: (46:12)

My advice is if it's financially feasible and in your schedule, just do it. Because the worst thing that could possibly happen is that it's mid. The best case scenario is that you find your community, you find friends, you go to...

seminars that really change your outlook on the disease and you have a really good time. The worst case scenario is that you go there and you don't really click with anybody and that is your first and last conference. But I bet you, you will have one of the better case

scenarios. You will find something in one of the sessions or in talking to somebody or going to

Going out, we don't always have scheduled things. Sometimes it'll be a group of adults who just goes out on the town and has a really good time with having this community at their disposal. you're always going to have, you're always going to find something really neat that is going to stick with you. And if you don't take that leap, then you'll never know.

JUDY WILLIAMS: (47:29)

Good

RUTH RAMA-WITT: (47:32)

think also the conference meets such diversity of needs, right? If you're there for information, for the science, we have it. If you're there for support group, for community, we have that. And now we've even really segmented that further, right? Judy, now it's parents who have alopecia and their kids. So I think I've seen the conference evolve from 2011 where

we're trying to really address all these different needs. So you can go there for the science, you can go there for the support, you can go there to learn about legislation and advocacy, like the work that Sabine is doing. You can go there just to make friends, not feel alone, just to know that there are people out there who have this. It could be as simple as that. I think there's just so many different ways that you can gain something.

from being at the conference. I'll bet my bottom dollar, you'll walk away and it'll still be positive no matter what slice of that agenda is that you might have for participating.

JUDY WILLIAMS: (48:45)

Great thank you Ruth I know what we're also having sessions at our youth camp for the siblings as we mentioned a while ago that siblings are part of the session as well. We know that this is a you know.

disease that affects not only the individual, it affects the entire family, right? And we've heard from even some siblings where sometimes it's difficult for them to approach their parents if it's, you they see that there's a lot going on with their sibling and everything they're going through. And some of these sessions, it's how to address, you know, that when they need the support as well and how it affects them as well. So it's like Ruth mentioned, and thank you for mentioning that it's really a conference for everyone in the family. It supports.

every every family member there. When you think about everything you gained from attending the conference, what stands out the most?

CLAIRE SHELTON: (49:43)

Learned about my treatment. It worked. You know, I mean, I think that conference can give you all sorts of different things if you just put yourself out there and try to learn stuff. I know

that it's scary to walk into somewhere where you don't exactly know what's gonna happen, like the first day of school, but.

There you will learn things either you will learn things make a friend gain the community or all three You know like you will be able to have come out of it with something for me the thing that stuck out was that I was able to Learn about this treatment and learn how to talk to my doctor about it That was really big like not only did I learn what it was I was then able to take that information And like bite-size it and then give it to my dermatologist. It was fun. Actually this dermatologist. This is kind of a side note

But this was a fun dermatologist appointment because I walked in and I was like, okay, doctor, you know, I learned about these JAK inhibitors and she kind of grabs my arm and she's like, I was going to talk to you about these today. And I was like, yes, you get it. And so I told her all about the conference. She said, that's wonderful. Yada, yada, So long story short, you can learn so much from conference. You can get so much out of it. I got treatment out of it, which is fabulous, but everybody's going to get different things. That's my answer.

JUDY WILLIAMS: (51:01)

Thank you. And I love you say that because then one of the things I've heard many times at conference is a lot of these attendees, when they're talking about treatments, they go there and they're asking all of these questions because they're not getting answers, right, from their local dermatologist or they can't find a dermatologist who can give them answers. And then we hear about dermatologists who are still unsure, don't know enough or are not well-versed on these new treatments.

consistently heard this. And as you mentioned, Claire, these are like the experts that you want to be talking to. one of the questions that one of the attendees asked was, well, what do I do when I take all of this, even if I learn and I take it back to my dermatologist, and he still tells me no, or tells me this isn't the right option? Dr. King just said,

You move on to a new doctor, go somewhere, another doctor and go to another one and after another one until you hear what you want, like you get what you're trying to do. It doesn't matter. Like you advocate for yourself, but the empowerment that, you know, these speakers, these experts just give our community members of just take it to advocate for themselves. And it's really great to see, you know, like you, Claire, how you were able to take that back.

and just advocate for yourself empowered with that information.

CLAIRE SHELTON: (52:30)

Yep. It was, it was really powerful. Dr. King, he was my guy. Rosé. I'm learning things this guy. It was him and I think Dr Craiglow she does the like, a lot of kids.

speaker-3 (52:36)

this.

RUTH RAMA-WITT: (52:43)

Yeah, they're they're married. amazing. I know. Cool.

JUDY WILLIAMS: (52:47)

What

CLAIRE SHELTON: (52:48)

Power

couple, alopecia power couple, that's all.

JUDY WILLIAMS: (52:53)

And well, you know, our time is up, but I want to thank you, all of you for this great webinar. this was great information to share, you know, this additional resource that we have through NAAF. We know it's a very empowering.

you know resource we understand it can be difficult but as Ruth mentioned we have programs even within the conference where like the buddy system to try to make things a little bit easier and how can we support you we've heard there's those who just go and then the first day I don't want to get out of my hotel room because it's so overwhelming there are people there even willing and able to like how can I help you how can I support you

So it's a great resource and we want to thank each of you for coming today and joining us and sharing your experience.

So if what you heard today resonates and feels like the next step, there is still time to join us at NAAF's 41st annual conference. It will take place in Orlando, Florida from June 25th through the 28th. And as Rooms mentioned, you can even make a vacation, many families still make a vacation out of it.

afterwards and the conference is the largest gathering of the alopecia areata community in the world and you're invited. It's a unique opportunity to hear directly from experts, connect with community leaders in alopecia areata and meet others who share similar experiences. We know travel costs are rising. So we did want to share that we have reduced our registration fees back to the early bird pricing.

helping save our community members \$100. So please register today. We'd love to see you in Orlando and we do have a financial assistance program as well that is still available for those who need extra assistance with registration or lodging. And thank you again to our panelists for sharing their stories and personal experience. To our audience, thank you for joining us.

Please share your feedback on today's webinar and help us plan for future presentation. And join us for our next webinar, a different kind of support. And this is with Let's Talk Dating and Relationships with alopecia areata, Real Experiences and Real Support.

scheduled for Tuesday, June 9th, 2026 at 7 p.m. Eastern Time, She brings together people with lived experience to talk honestly about dating and relationships with Alopecia areata, what's been challenging, what's helped, and how each person's journey can look different.

registration for this webinar is now open. And we encourage you to stay in regular touch with NAAF. Use the QR code here to subscribe to our email list for regular updates on alopecia areata, 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 naf.org or email us at support@naf.org.

And this concludes today's webinar. Thank you for joining us and we look forward to seeing you on the next webinar. Thank you all.

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