



Beyond First Impressions: Alopecia Areata, Social Media, and the Power of Your Story

Sept. 24, 2026 – Lindsay Walter

JUDY WILLIAMS:

00:00:01

Okay, we'll get started. Welcome to the National Alopecia Areata Foundation's webinar, Beyond First Impressions, Alopecia Areata, Social Media and the Power of Your Story. Joining us today is Lindsay Walter and I'm Judy Williams, Director of Community Support for NAAF. Before we do start the webinar, I'd like to cover a few housekeeping details. We have disabled chat for this webinar session, so please post questions for our panelists or for our speaker today in the Q&A section. Please keep your questions general for the benefit of all the audience members and the webinar is being recorded and all of the registrants will receive a link to the recording via email. And finally, please share your feedback with us at the conclusion of this webinar. a link to a short survey will pop up in your browser.

And so please complete the survey there. And we like to use your input to plan for future webinars. Note that this live captioning is available for this webinar. So 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. NAAF gratefully acknowledges the support provided for this webinar series by our partners, Eli Lilly, Pfizer, and Sun Pharma. 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 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's support resources and research and advocacy activities, or to join us as an advocate or supporter, please visit our website at NAAF.org. And we know that it can be confusing to hear all of the terms used to talk about alopecia areata, from 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 1 disease, the autoimmune disease alopecia areata.

That's what we are here to talk about today. And now on to today's webinar, Beyond First Impressions, Alopecia Areata, Social Media, and the Power of Your Story. Today, we're joined by an inspiring advocate who has transformed difficult experiences into a powerful platform for education, awareness, and resilience. Lindsay lost all of her hair at age two and has been on what she describes as a roller coaster journey with alopecia. a journey she now sees as the greatest gift that she never knew she needed. Originally from Wisconsin and now living in North Carolina, Lindsay is a run coach, marathon, and ultra runner, and we're grateful to have her here with us today to share insights and experiences. Welcome, Lindsay. I'll stop sharing.

LINDSAY WALTER:

00:03:36

Hi, thank you so much for having me.

JUDY WILLIAMS:

00:03:38

Hi, Lindsay. Well, thank you for joining us. I know I've been following your stories and a lot of articles that I've read about you. And you are also, one thing I didn't mention is that you are also a support group leader for NAAF, for a children's support group. So thank you for everything that you do. But today we want to talk a little bit about your experience, how you were diagnosed at an early age and how that has transformed into, giving

you your voice to advocate for those who have alopecia areata. So we'll get started with letting you tell us a little bit about your story, your journey.

LINDSAY WALTER:

00:04:16

Okay, so yeah, as you mentioned, I lost my hair at 2 years old. And so at the time, there was no one else in my school, community, social media wasn't really a thing, so it was super hard growing up just not seeing anyone else who looked like me. I wore a wig really since I can remember, since I was in preschool, and I think I just felt so isolated and lonely and just really hid under my wig. I didn't know how to talk about alopecia. I had no one to talk to with just because I felt like no one truly understood, and I think the older you got, it's just something you try to figure out. And I never wanted to accept that my hair wasn't going to grow back. I struggled a lot just not having eyebrows that are now tattooed on, not having eyelashes and everything.

Kids were unfortunately just super mean to me when I was in school. And I think I just tried to hide my wig so much. I played sports. I was a basketball player in college all through high school, and I can just remember the lengths I went to to just hide my alopecia the double-sided tape, I would be sweating so much. I remember going into the bathroom stall at halftime, the coach would shout out four minutes left and I was so stressed out that I was almost in tears because I was trying to take off my wig and then fix my cap and re-dry it off so I could retape it and just, it would rip open my head, the scars, the bleeding and just all of that. And I just really struggled because my goal was for no one to know that I had alopecia.

I think you just add on also being a female, that's hard in middle school, that's hard in high school and really just life. A lot of times you're just focused solely on your appearance. And I think just not having anyone else to talk to about that also was really hard. I was just taking on so much, just such a burden and I didn't know how to talk about my alopecia. I was so embarrassed and ashamed of it.

So I struggled for a good, yeah, like probably 20 years I hid under my wig and even through college, old college basketball, kind of the same thing with just my wig, hiding underneath it. And it wasn't until after college that I started running marathons. And I think there's something so empowering about running. You're the one running, you're putting in the miles, you're the one doing all that versus a team sport.

Obviously team sports are great and bring so much, teach you a lot of lessons, but running was just, you know, a self sport. And I loved that so much. The more I was running, the more I was gaining confidence in myself, really just embracing and feeling so strong and empowered. And that's when I stopped wearing my wig, through my running journey. And I think also getting to a point of, I lost my hair too, my hair is never coming back. I really just got to a point in my young adult life where I just was like, I need to accept that. This is my reality, this is my life, and there's no reason to be ashamed of having alopecia. That's when I started getting involved, reaching out, finding other people who have alopecia, connecting with them and putting myself out there was really, really scary for me, just talking to someone about it.

A really great group of close friends who I told about my alopecia to and just found a really great support system. So that also helped me a lot too, kind of setting small goals along the way, like in running, training for races and marathons, kind of the same thing. I would be like, okay, I'm gonna go to the grocery store without my wig on and wear a scarf or wear a hat or something like that till I felt totally comfortable. And I always had this kind of, lifelong dream, I guess, to be just comfortable and confident in my alopecia journey, whatever that looks like, whether that was wearing a wig, not wearing a wig. And for me to get to a point now where I don't wear a wig and that's how I feel the most comfortable and beautiful.

It took me a really long time to get there, but I've just seen alopecia for just truly, like I've said many times, just the greatest gift I never knew I needed. It has just taught me so much about what matters in life. It's taught me empathy, it's taught me strength, how to be kind to others, and made me just a really, I mean, obviously not like a perfect person or anything, but it's just really taught me a lot and like made me who I am today. It's made me a better runner. It's made me a stronger runner and just super resilient and also has inspired me so much to just give back to the alopecia community as just a mentor and encouragement to share my story. And when the opportunities come to not be afraid of sharing my stories, the good parts of it and also the hard parts of it.

You know, you think as you get older that people will never be mean to you that life just gets easier, that's unfortunately not always the case. And I have experienced that quite a lot in my adult life, which is also something too, when I think back, that was one of my biggest fears when I was really struggling with my alopecia is that I feel like I had to wear a wig because I kind of blended in with everyone and now I stand out and I never wanted people to be mean to me. I never wanted people to judge me. And that was one of my biggest fears when I was a kid. It unfortunately came true in my adult life, but I think learning to navigate through that has really like taught and shown me a lot. Yeah, I guess that's kind of my story in like a nutshell.

JUDY WILLIAMS:

00:09:33

Thank you, Lindsay. You mentioned in your story, how part of it is you want it to blend in, which is one of the reasons, right, that you wore your wig and you've experienced people being negative or even possibly bullying. I don't know, throughout school, you did go through the elementary, middle school, high school, experiencing all of that. How do you feel, and I know we've talked about briefly, I mentioned, I know you've done several articles, you've done, you've created a social media platform for yourself, describing some of your experience, sharing what you've experienced. How do you feel overcoming that fear?

Obviously, right? It was the first thing you didn't want the attention. And when was it that that turned into using what your experience was to really advocate for yourself and for others?

LINDSAY WALTER:

00:10:31

Yeah. I would say, you know, I think going through really hard experiences makes you really appreciate the really good experiences and the really good season. And I think the older I've gotten, the more people I've gotten to know in the alopecia community, just knowing I have so many kids and people looking up to me. It really, I think that like really kind of encourages me when I feel down.

And I think it's important to obviously share like the really good moments and, you know, really positive things about my alopecia and all it's taught me, but also sharing like the real stories and the hardships because like it's not always going to be easy. I think it's really important to be authentic and genuine about that and not sugarcoat that. And because alopecia, you know, it's not just your hair and so an emotional rollercoaster.

And I think just also realizing again, this took me a while to get to this point, but when someone is mean to me, it is not a reflection of me, but it is a reflection of them. And I think always knowing that I have chosen to take the high road not respond back negatively, and to just bring awareness that has created so many opportunities to create awareness when I have gotten comments about my bald head, people thinking that I am not feminine.

I think especially in the running world that has happened quite a bit. And not that it hasn't hurt my feelings, because of course it has. I am sensitive and that it's just who I am. But I think instead of feeling like discouraged and down about that, I know that that is not true. And just turning the narrative into one of encouragement and truth, instead of that bringing me down, I'm like, no, I'm gonna share this moment as hard as it is. And I guess almost embarrassing a little bit that I have felt on several occasions using it for awareness and education because I think that's so important. Not everyone knows about alopecia, which is fine, but then shining a light on that. So I think using it as well and turning it into a positive narrative.

JUDY WILLIAMS:

00:12:29

Okay, great. Thank you. And we have a lot of, I know we've heard a lot from a lot of parents or young adults who say it's really difficult with now with social media. as you mentioned, like the pressure of having to fit into a particular, you know, the looks the way somebody should look, and you're talking about perception that somebody perhaps confused you, right, not being feminine. What would you say to these parents or young adults or teenagers that are having a hard time as they are, you know, they are on social media, or what message would you give to them just to kind of empower them, possibly give them kind of a warning of how to not focus on that side or how would they be able to reflect and not let them just overwhelm them in that sense.

We've heard that a lot. Like they feel a lot of the pressure that they feel possibly isn't even coming from a person, another individual. It's what they're seeing on social media.

LINDSAY WALTER:

00:13:35

Yeah, I think there's a lot to be said about social media. I think there is, and there is a lot of really positive things about it, but it can be also something that can just be so negative and allow you to doom scroll and feel bad about yourself and everything. And I would say that there's nothing wrong with blocking people. You're not the mean one. That's something again, I had to learn. If a mean comment ever comes through to me, not even responding, I just block that person and delete the comment.

And I think kind of out of sight, out of mind type of a thing. So that's something that I do. And I think too, just whether you have a private account or a public account, I think if, obviously that's a choice you have to make depending on your age, depending on what your parents say and kind of all of that. But if you do choose to go down that road, just know that people are not always gonna be nice. And it's just something unfortunate that you just have to accept just given what social media is.

And I think, people are gonna comment no matter what. And as long as you know like who you are and like what is true and like what you believe in and just feel confident in yourself, I would say that, but just know that, you know, people will hide behind a keyboard. People will make comments. You know, hopefully it doesn't happen or it doesn't happen often, but it is probably probably unfortunately going to happen.

And I think like when that does just make sure that you don't read into those comments, you don't let it, you know, spiral into something really negative about yourself. And if you see something like that, just step away from it. I think it's really important to have healthy outlets and to use social media for something positive, but like that is not the truth. Um, so don't be fully dependent on social media and, um, Yeah, I guess make sure you have a great support of people, a great network, and reach out to people in the alopecia community. Everyone has had very similar experiences, and I know the majority of people would just love to help and encourage people.

So reach out to people, ask for support, ask for help, and just know that social media can be really great, but just because someone says something about you doesn't make it true.

JUDY WILLIAMS:

00:15:45

Right, thank you for sharing that. What would you say again? You briefly touched on that when you shared your story. What really was it that motivated you to? share your story and just kind of empower you? What is it that because you're not only at a on a platform level, like we've seen articles about you, you really go out and voice and advocate. You're also a children's support group leader, you've done a lot of things involving yourself and see how you can make a change for yourself and for others. Is there a reason why you did this? Did this help you with your own, you know, with your own journey?

LINDSAY WALTER:

00:16:29

I think a couple of things kind of come to mind with that. I think, growing up, I mean, I just turned 36. So, growing up where, again, social media wasn't around, I didn't have anyone else. I know like how isolating and lonely that felt, just having no one being able to say, I walked through that and I understand that. And I think like that is so powerful. And so just, wanting to just be that person that I needed when I was younger. And I know it just would have made a world of difference for me had I read articles about someone or saw them on the news and just, I would have not have felt alone.

So I think like that's part of it. And I think also when an opportunity comes my way, as amazing as it is for me to share my story, if it can just help encourage one person, I think that's like so important and it's just such a special honor. to get to bring awareness and education to alopecia. And I think the more that people are able to do that, the more people, you know, learn about it. And if I can just like help people, I think that is just everything to me and that really means a lot. And I think, yeah, I would say that probably.

JUDY WILLIAMS:

00:17:43

Okay. You're obviously a huge athlete, right? You do marathons. And so a lot of people, we do hear from others in teenagers or those in high school or college. You mentioned this briefly, you know, about how you worry about, you know, your wig and not, and there are some who still want to camouflage. What are your tips or what is it that did you find it best to share that with your coach? Like what would you offer as a support or guidance to those young people or community members who are going through that right now.

LINDSAY WALTER:

00:18:19

Yeah, I would say one thing I always tell people and just really believe in is that your alopecia journey is your journey. It's going to look different than everyone else's. We all experience alopecia in a different way. We have to do what feels the best for us and makes us feel the most confident. So if that's wearing a wig, if that's going out bald, maybe you wear scarves, just whatever you need to do, make that choice that is right for you. You're the one that has to live with alopecia and how you show up in the world day in and day out. That might change over time. You might go through different seasons of that, but just first making that choice that's right for you and there's no wrong way to have alopecia.

I think it's hard. You first have to make make that choice. I will say when I was younger playing basketball, AAU basketball and just everything, I used double-sided tape and that worked for me. Obviously there was instances where I needed most games of halftime just because I would sweat so much. I needed to go and change out that tape. And yeah, I would say that for me, my wig that I wore had an adjustable cap.

And so I would honestly pull that so, so tight. It would ingroove in the back of my head, but I just needed that wig to feel secure. And that, again, for me at that time in my life is just how I felt the most confident was having a wig. And so for me, that worked. I did that for also several years when I first started running just with marathons, wearing a thick headband, so it's kind of hiding the cap of it.

And then, for me, that's just how I felt the most confident. And then when I was younger, I also got my eyebrows tattooed on. I think for me, just having that also helped me to have confidence just to kind of see like where my eyebrows would be when I do wear makeup and get dressed up. Being able to fill those in, that's something that does help me feel more confident though. Again, I think everyone is different, but that's kind of all I know. Since I was in middle school, I got my eyebrows tattooed on again, just to blend in and to fit in with everyone else. I know like times have changed so much.

So people are like doing different things. You know, makeup has evolved, putting on eyebrows had evolved and all of that. And again, what I would also say with that is just doing what feels right for you and what makes you feel the most confident. There is absolutely no shame. And whether you wear a wig, you don't wear a wig, you want to put on eyebrows, you want to put on eyelashes. There's just incredible products out there if that's what you choose to do or not at all. You just rock your bald head and your natural face.

I think that's awesome too. Just being confident in like whatever that is. but it's gonna come up when you play sports, especially, wearing a wig, doing your makeup if you do that. And I think there's really no way to avoid that, but there are definitely ways that you can keep that secure. And I think it's so important to also make sure that your coach knows about that, your teammates know about that. And just being super honest and upfront about that because I've learned in team sports most of the time the girls are going to have your back.

So if something would happen, just making sure they know about it. And then just being honest with your coaches too, or maybe there's like some kind of signal or something. If something happens in your cap like slips up on your wig, I had that and that always helped me feel secure too. It was just like a hand gesture I could give. And so doing that also as well. But I think you also need to be like honest and upfront about that too, just with your teammate and coaches.

JUDY WILLIAMS:

00:21:53

Okay. Thank you. And you mentioned, you told us that your journey has been the greatest gift that you never knew you needed. Can you tell us a little bit about that?

LINDSAY WALTER:

00:22:06

Yeah, I would say, you know, when I was younger and I was like really struggling with my alopecia, I was like, this is the worst thing. Like I never saw anything positive about it and I never, imagine that I would get to live, I guess, like a normal quote unquote life, whatever that truly meant as a kid. And then I look at my adult self now and here I am sitting here getting to talk about alopecia, getting to bring awareness and all the opportunities that have come my way to bring awareness and education, to just share stories and share moments and just, yeah, I guess hearing things from people as well that like, wow, I saw your story and I feel so encouraged by that. or anything like that and it hasn't.

It's made me such a better person than I don't know if I would have turned out the way I did. I don't think I would have been as empathetic as I am now. I don't think I would be as strong, as empowered and really learned what the true meaning of beauty was. I think until you walk through something really hard, you don't really. know kind of what that's all going to do for you and how much it's changed me and it's changed me for the better. Hasn't always been easy. There's definitely times where I'm like, even in my adult life where I don't feel grateful for my alopecia and I'm upset by it and I'm frustrated by it, which are all normal and acceptable emotions.

But I think also like, no, this is who I am. This is how I was made and this is what I have. And instead of letting that turn me into someone really bitter and upset, I'm like, no, I'm going to turn this into something positive, make the most out of it, help other people and, you know, like kind of be proud of who I am and the growth with that. And I think turning it into something positive has been really, really great.

JUDY WILLIAMS:

00:23:47

Great, thank you. And we're getting a lot of questions. So if it's okay, we're going to bring in a few of the questions, start asking them of yours. One of the first ones, it's, do you feel running marathons affect your alopecia in a positive or negative way physically?

LINDSAY WALTER:

00:24:09

Both. I would say So right off the bat, obviously I stand out when I'm in the starting blocks. And I think instead of looking at it as a negative, looking at it as a positive, it has allowed so many people to come up and say something to me. A lot of times people do assume I am going through treatment. They tell me, wow, you're so brave. I hope you can finish this marathon. And instead of being hurt by that, or getting up to I'm like, no, I have alopecia. And it's just such a conversation starter, think in the running world and athletics, just being able to say that and bring awareness to alopecia.

Obviously standing out a lot at marathons, there's been several opportunities where, you know, after the race, someone or like a news station or like The local news and whatnot has been like, oh, tell me about your race. And I'm like, oh, I have alopecia. And just kind of right off the bat, because I know what people are going to ask me. So I've gotten to bring a lot of awareness to alopecia.

And so I think looking at that as a positive, also too, not that it has never been a negative experience for me, because it definitely has. There's been several times, I think, also just kind of what's going on in the world today as far as people thinking that I am not a female and that I shouldn't be racing in the female category. I think that has also been something that I have had to go through quite a bit. So I think obviously that's a very negative experience and that can be really hard. But yeah, so probably both.

JUDY WILLIAMS:

00:25:34

Okay, thank you. Somebody asked, you know, as we're talking about you running in your marathon, somebody actually asked, how do you keep your head warm when needed and the cold when needed with no hair? This community member says, I became aware of all that hair does for one's head and temperature regulation.

LINDSAY WALTER:

00:25:55

Yeah, I notice as soon as my head gets cold, I get super bad headaches. And so when it's cold outside, I have to wear a beanie. I find if my head is warm, that I'm totally fine running out in any weather, but I always have to wear a beanie. I always have to make sure my head is warm. Definitely head and ears. And yes, it does make a huge difference. Yeah, head.

JUDY WILLIAMS:

00:26:16

And if someone asks you about not having hair and you aren't in the mood to engage with that person, what tips do you have to handle that situation and get out of the conversation?

LINDSAY WALTER:

00:26:28

Yeah, I think protecting your peace and protecting your heart, you never need to apologize and you never need to feel bad for that. I think obviously not getting upset at someone for asking a question, but I think it's just a simple, I don't want to talk about that right now, or I have alopecia, and then just walk away, excuse yourself from the conversation. I've learned too, that's something that I have had to work on too, because I never want to be rude to someone or anything like that.

But there is, I mean, not everyone has a right to know your business. People don't have a right to come and ask you questions, especially if you just like don't want to talk about it. You simply want to Just be in the world. You wanna just go to the grocery store, buy groceries. You don't wanna have to talk about your alopecia and there's nothing wrong with saying that to people. It's not always easy to do, but yeah, protect your peace, protect your heart. If you don't wanna talk about it, then you don't need to talk about it. Not everyone needs access to you.

JUDY WILLIAMS:

00:27:20

Okay, good. Good response. Thank you for sharing. And what did your parents do that were helpful in supporting you on your journey, especially as a teenager?

LINDSAY WALTER:

00:27:33

I would say just, I knew that they were always there to talk to. I didn't like talking about my alopecia, but I knew that they were there if I wanted to talk to them. And I think too, the older I've gotten, the more I've seen, like, you know, sometimes you just as someone with alopecia, sometimes you're like, I don't want to talk about it just because you're internalizing a lot of stuff.

But I would say, I mean, I'm not a parent, but just knowing that you're there for your kids and saying, I'm there to talk about it whenever you want to talk about it. If you want to talk about it and you might seem like, I don't know if I'm helping them or not, they don't ever want to talk about it, but they know that you're there and you can never say that too much. You can never say I'm proud of you and I love you and just saying that over and over again.

So they know that you're there whenever they do want to talk about it. And I think also just letting them lead with their alopecia, whatever that looks like. Again, whether that's wearing a wig, not wearing a wig, makeup, no makeup, just whatever that looks like for them. I think just letting them kind of take the lead on that and what they want to do and how they want to handle their alopecia.

Again, they're the one that lives their alopecia day in and day out, whether it's at school and whatnot, and just helping them feel the most confident, whatever that looks like for them. And I think sharing opinions, but also having honest and real conversations with kids as well, especially I think when you get to be a teenager. Yeah, just being able to talk about like the real hard things. And I think sharing opinions, what you think of course you're the parent and then just listening to what they have to say too is just really, really important.

JUDY WILLIAMS:

00:29:12

Okay, thank you. And has your alopecia affected your ability to make friends?

LINDSAY WALTER:

00:29:19

Yes. I will say the older I've gotten, I've learned that alopecia is such a great filter. I wasn't always thankful for it and I didn't always think that way, but I think yes. And I've had just several experiences again, the older I've gotten as well. And when I really stopped wearing my wig, it made other people feel uncomfortable just because you know, you do stand out, you do look different.

And so some, and that's, you know, speaking to them and their insecurity and it's not yours, but anyone who wouldn't want to be around me because I draw attention to myself by simply not having hair isn't a friend or person that I would want in my life. Again, that's not an easy situation to go through to have someone not want to be your friend, not invite you out with them because you stand out and you're different and it's not easy to go through that. And it can be like really, really hard to deal with.

But at the end of the day, just knowing that isn't a friend or person that you would want in your life. Again, it's not easy to walk through that and it doesn't feel good, but it is the best thing for you.

JUDY WILLIAMS:

00:30:25

Okay. And you mentioned earlier that one of the things that you struggled with right early on, you didn't have a lot of other people who had alopecia areata, and that for that support, you also lead a children's support group. What would you say as a support group leader and then knowing your personal experience and what you now see the children when they participate in these support groups? the importance of them or perhaps like what is it that you're hearing or seeing in these support groups that truly are helpful for the parents, perhaps for the children, what type of engagement do you see, etc.

LINDSAY WALTER:

00:31:05

I think being a part of a support group or even just knowing one other person that has alopecia is so important and so life changing. Again, you may be someone who is having a really hard time with your alopecia. You may not want to talk about it. You may be struggling with it. But if you just are in a group or with someone else who has alopecia, just to see that, unless you've experienced that, it is just such an unspoken comfort to be like, wow, that person looks just like me. And even if you don't talk, because maybe you're shy or whatever the reason. You just feel so comforted that and you can see someone else with alopecia.

And so I would say if you're able to bring your kids to support groups, whether it's in person or it's a Zoom or it's the conference or just anything that you're able to do, absolutely do it. Again, they might seem like, they're not engaging. I don't know if that was worthwhile. They absolutely are. It's internalized. Even again, just being around other people that have alopecia, you just have this bond, even it's just like an unspoken bond and you just have that.

So I would say as much as you can bring just exposure and experiences to being around others with alopecia, I think that's so important. And it just helps you so much, I think, to just being able to say, I understand and I walked through that. I think that's such a powerful thing, which made me want to be a support group leader and just give back and mentor kids. Because again, I think something too that I struggled with a lot growing up is when someone would say to me, oh, I understand. I understand it was coming from a kind place. I was like, in my mind, I would just think you don't understand. You have hair. You cannot possibly understand what I'm going through right now.

And so for me, that was just because I felt like no one understood. And then now I get to say like, no, I understand that like I have not had hair basically my whole life. So I do understand what that's like. And I think being able to talk about real emotions and that there is also, it's totally fine to not be okay with your alopecia. You're not gonna love your alopecia every day or even for a season. Like it's gonna feel hard and there's nothing

wrong with that. You're not, you know, less of an alopecian because you want hair or because you want to wear a wig. Like there's nothing wrong with that. It's actually a very normal feeling.

Again, we all, our alopecia journey is different for all of us. We feel confident in different ways through our journey. And I think like that's so important to do like what is right for you. But the more you can just be around other people with alopecia, I would also think as like a parent as well. the more you can connect with other parents who son or daughter has alopecia, just having that bond and connection and being able to talk about that, I would think that that would also be really helpful for you just to also share experiences as well. So I would say, yeah, the more you can be involved and the more you can do, the more it just helps just being around others.

JUDY WILLIAMS:

00:34:03

Okay, and we have a follow-up question with that is, what if my child doesn't want to attend a support group, what would be a good way to encourage them?

LINDSAY WALTER:

00:34:14

So I absolutely understand that feeling. I can say my first large gathering, I was blown away, but I was also so overwhelmed with it. I think it's a lot to go, you don't really know anyone else with alopecia and then you see so many people with alopecia. It's a very overwhelming feeling. and so you're going to go through different emotions with that. I would encourage them to just keep going. Um, even if they don't want to go, obviously, I don't really know how much you can, you know, push your child and make them go, but I would just keep encouraging them. Um, or even if you could just do like a one-on-one event, maybe going to like a full in-person support just maybe isn't right quite yet, um, which is totally okay.

Maybe there's someone in the group that you can reach out to in one-on-one like go for a coffee or like go to the park or something like that kind of one on one if that would be a little easier if that's not quite an option for you. There's just so many incredible just stories of different alopecians, just like news articles or videos and stuff like that. And I think the more you can kind of show that, be like, oh, like, that person is running marathons or that person is, a football player or just like so many stories.

I think the more you can kind of show stories of just people living their lives with alopecia and kind of help them feel encouraged with that, and it might take a long time. I've seen it happen in the beginning, someone doesn't want to go to an in-person event. again, totally fine, totally understandable. But the more you can kind of slowly encourage them, show them news articles and just so many people out with alopecia, I think eventually they'll get to that point, but not to feel discouraged if people don't want to go right away. I would just say like hopefully kind of just continue to like encourage that.

JUDY WILLIAMS:

00:36:04

Okay, thank you. Another question is, do you think social media has changed the way people with alopecia connect with one another compared to when you were younger?

LINDSAY WALTER:

00:36:15

Yeah, I would say, I mean, honestly, social media was not a thing when I was younger. And I think now you just see so much with like how people can connect with others. You see videos, you just see so much. Whether it's like a get ready with me or it's someone doing athletics, there's just so much that you can have access to. And I think that can be a really positive side of social media.

I also think that can put pressure on people to think like, oh, well, that person's so confident with their alopecia, like I need to do that. Or that person, you know, is wearing makeup and wigs and like eyelashes and I need to do all of that, right? So I think sometimes it can also put pressure on you to kind of be a certain way or to act And I would just strongly encourage people to just keep doing what feels right to them and what helps them be the most confident.

And I think also social media really only tells one side of the story, right? So I think you see people and you're like, oh, well, she's so confident. She loves her alopecia. Like, oh, I wish that was me. I wish I did. I guarantee there's so much going on behind the scenes. Like maybe in that moment, alopecia was like really, really, a really great moment and they felt really happy by their alopecia, but that's also not reality. I have not met, and I've met a lot of people with alopecia, I have not met one person who didn't have a really hard season or moment. So I would think also to remind yourself that it is social media. It's not always real and people do struggle. You just don't always know about it.

JUDY WILLIAMS:

00:37:45

Thank you. And what would you say to someone who wants to tell their story? I know we were talking about the power of your story, how you've used your experience to touch others, to advocate. But what if they're not ready? They want to share it, but they're just not ready to be vulnerable publicly.

LINDSAY WALTER:

00:38:09

Yeah, I would say write down your story to begin with and kind of write that out. And it's going to feel so therapeutic and very empowering when you're writing out that story. You don't have to talk about it. doesn't have to be out loud, but it's going to feel really good to kind of get that off your chest and to kind of say what you want to say without thinking that anyone is going to respond or say something negative, right?

So I would say write out your story. And then start small, like share it with your family, share it with a close group of friends. Maybe you eventually share it with like your class at school or something like that. But like start off small and don't feel discouraged in your story. All of our stories are different. All of our stories are messy. All of us have, you know, went through really hard things.

And I think, you know, it teaches us so much and we can all connect and learn from each other's stories, but like, Don't be afraid like you have alopecia for a reason and use it to empower and help other other people.

JUDY WILLIAMS:

00:39:08

OK, thank you. And you know, obviously you were diagnosed at a very early age, so you went for a long time. You understand you know what it is to have to have alopecia areata as a child. But now that you also have a support group with children who have alopecia areata, what would you tell parents? or that you wish that adults understood a little bit better about alopecia and their journey as a child?

LINDSAY WALTER:

00:39:38

Yeah, you know, it's gonna be hard. It's so much more than just your hair. Again, until you've kind of walked through that, you don't really realize like the emotional toll that it is. And I think also too, just kind of being aware. Again, I know no one would like in touch, no parent would intentionally do anything that would make their kid feel bad about themselves, but I think too, just like being mindful of the way you talk about hair, I feel like, my hair is so ugly.

Again, you don't, but if your child doesn't have hair and they hear you say that, then it can just kind of. kind of make them upset or angry. Again, totally like a totally innocent comment that you make or I'm having such a bad hair day. Again, I just think it's like little things like that just kind of you do have to be a little more mindful of like what you're saying or the way that it's like presented as far as like, oh, like going to the hair salon and things like that. Just never. wanting that in front of your kid, I can say, especially from just being a young girl and not having hair, seeing other people, especially the older I got when I was going to dances in high school and things like that, and just like, everyone gets to go to the hair salon and get their hair done.

I was wearing my wig, so I kind of could, and it could be curled, but not to the extent that everyone else got to, or just depending on what you're going through, that can be a super hard season to navigate. And so I think just like being super mindful of just kind of stuff like that and just, yeah, I would say probably that.

JUDY WILLIAMS:

00:41:08

Great. And do you feel like, do you have any regrets about how many times you've shared about your journey on a public platform? Like, do you wish you would have shared more or how do you navigate that as You start off small, right? Just telling a few folks. Then you've gone as far as actually in a public and a public platform, you know, articles that were written about you. How was that transition? Like, what do you think? What would you do differently?

LINDSAY WALTER:

00:41:40

Yeah, that's a good question. Yeah, I think, you know, in the beginning I was really, really nervous just because I was like, oh man, people are going to judge me. People are going to be mean to me. And I think I just didn't grow up just having super tough skin. I never knew how to respond back to people. It was never a thought in my mind when someone's mean to me to be mean back to them.

And so I think when people have been mean to me, I've really kind of struggled with like, oh my gosh, I can't believe they would say that. What do I say back? I think, you know, just, you know, knowing that there's power in my story and there's a reason for my story and I'm helping more people than I probably even realize. And so I think just not being afraid of that, not letting some, like the fear of other people kind of deter me from sharing my story or feeling self-conscious about it.

And I think also too, just knowing that people are gonna respond negatively or not always have something nice to say. But again, that's their problem. And also to not kind of worry about it. Again, easier said than done. But I think I've learned just to delete comments, delete negativity, not even respond to things. And if I see it, I'm like, oh. There's been times where I've had a Reddit thread just absolutely ripping me apart.

And I think just not engaging in that, not looking at that, as tempting as that might be, but just knowing it's going to hurt my feelings and so just not. And I think just setting a healthy boundary with that, but also looking at any opportunity that comes my way to bring awareness and education, just how important that that is and that it's going to help people. So I think that really keeps me like motivated. And if I do have like a moment where I'm like, oh, I don't know if I want to do that. I'm like, no, like that's going to help someone. I absolutely need to do that. So just thinking of all the people that I know like look up to me and what an honor that is and really taking that seriously.

JUDY WILLIAMS:

00:43:44

Great. Thank you. And to end, I think that's a great way to end. But before we do, I would just say, you have, you obviously do so much for the alopecia areata community and thank you for that. But what would you tell others how this has helped you? How would you encourage them like to give back? Whether it's, you know, it doesn't have to be as a support group leader, it doesn't have to be sharing your story through a news outlet or perhaps just being a mentor. or doing the walk, what would you tell others how this, you know, how it helps you through your journey with alopecia?

LINDSAY WALTER:

00:44:23

I would say that really there's like no act that's too small. I think whatever that looks like for you, whatever season you're in, whatever you can do to help someone else and just encourage someone else. Obviously, everyone here is connected to alopecia in some way, but I think also too, whether you're a kid and you have alopecia, just being a friend of someone else, right? Let's say you're at an event and you see someone kind of sitting by themselves feeling really shy and nervous, just going up and saying, Hi, my name is Lindsay. We both have alopecia. And just doing small things like that, that really will change someone's experience in someone's life, and they're going to look back at those moments and say, That was my first alopecia event I went to I was so nervous, but then this girl, Lindsay, came up and she said hi to me.

And that was my first LLP front, right? You might not think saying hi to someone in an event might make a difference, but it absolutely will. And I think, yeah, just no matter what you can do that's going to help someone

else, whether it's being in support group, attending events, or just, just any way you can kind of help and be a friend to someone else and an encouragement to someone else, it really will make a difference and it really will stick with them and you might never know it.

But if you can just be kind to others as well, and I think lead by example, I think that's also one of the greatest things that just we all can do in general, just the way we respond to situations, just the way we lead. I think that's like really, really important too.

JUDY WILLIAMS:

00:45:49

Well, thank you, Lindsay. What a great way to end this. And we actually just had somebody message on the send a comment saying, thank you, Lindsay, for reminding me that an alopecia walk was created by a young girl here in Syracuse on Saturday, and I just signed up to join her. So thank you for the reminder. You know, whether they have alopecia areata or they're a supporter, a family member, you know, I know it helps. all of them through that journey and they're all as a family unit just going through that journey along with them.

So thank you for sharing that and it was great having you. I'll start sharing my screen. Okay, thank you again for sharing today all of your wisdom and your experience that you've had and for sharing your story and your personal experience. And to our audience, thank you for joining us today. Please be sure to share your feedback on today's webinar and help us plan for future webinars. A link to a short survey will be popping up and your feedback is truly appreciated. And as Lindsay mentioned, I know we're only days away from our upcoming event this weekend that shines a bright light on alopecia areata. There's still time to register, find the closest one to you. It raises critical funds and helps show the world that it's not just hair.

The National Alopecia Areata Foundation's fourth annual Walk for Alopecia is presented by Pfizer and as the grand finale of Alopecia Awareness Month, the Walk for Alopecia brings together individuals living with alopecia areata, families, caregivers, friends, coworkers, healthcare professionals, and supporters from across the country for one powerful day of awareness, connection, and impact. Together, we create hope, build community, drive progress, and help end the stigma surrounding alopecia areata. This walk is a family-friendly event that celebrates and honors everyone affected by alopecia areata while raising funds that enable NAAF to advance research, provide support and education, advocate for the alopecia areata community, and increase public awareness of this autoimmune disease that affects nearly 7 million Americans.

It takes place on September 26th. Whether you join us at one of our flagship events in San Francisco, Philadelphia or Boston, you can still participate at one of our 40 plus volunteer led community walk sites or gather your own team and walk where you are. There is a place for everyone to be part of this movement. So we invite you to join us. You can still learn more and register, there's still time and together we can create awareness. inspire hope and make a difference for everyone affected by alopecia areata.

So we hope to see you there 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. So to learn more about NAAF and the resources we offer, please visit [NAAF.org](https://www.naaf.org) or email us at support@naaf.org. And we have a lot of great support groups. Just as Lindsay mentioned, there's for parents, for children, general support groups for teenagers.

So please go visit our website and find the support group near you. And this concludes today's webinar program. Thank you again, Lindsay, for sharing your story. We were so honored to have you. Thank you for joining us and we look forward to seeing you on the next webinar.