



Navigating Alopecia Areata in Skin of Color

Dr. Victoria Barbosa

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JUDY WILLIAMS: [0:02]

OK, we'll get started. Welcome to the National Alopecia Areata Foundation's webinar, Navigating Alopecia Areata in Skin of Color. We are honored to have us have us joining us today, Dr. Victoria Barbosa and I am Judy Williams, Senior 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 for our speaker in the Q&A section. And please keep your questions general for the benefit of all audience members. This webinar is being recorded and all our registrants will receive a link to the recording via e-mail. 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. Please complete the survey there and we use your input to plan for future webinars. Note that live captioning is available for this webinar. To turn on the captions, click the CC Show Captions button on your Zoom toolbar. The captions will appear automatically at the bottom of your screen. And this webinar is part of NAAF 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. And 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 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 the terms that are used to talk about alopecia areata, Patchy, diffuse, Ophiasis, totalis, universalis, mild, moderate and severe.

JUDY WILLIAMS: [2:30]

The NAAF 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, Navigating alopecia areata in skin of color. We are so delighted to welcome Dr. Victoria Barbosa today to today. Today's webinar. One of the most highly rated and requested speakers at NAAF Annual conference. Dr. Barbosa is known for her dedication to supporting people living with alopecia. Dr. Barbosa is associate professor of Dermatology and director of the Hair Loss Program at the University of Chicago. A nationally recognized expert in hair and scalp disorders, she is passionate about advancing care, education, and support for people living with alopecia through her clinical work, research, patient education, and community outreach. Dr. Barbosa has published and lectured extensively on hair loss, dermatology, and skin of color and leadership, and was recently recognized by the American Academy of Dermatology for her contributions to advancing health equity. Dr. Barbosa, thank you so much for being with us today and for sharing your expertise with the NAAF community. So without further ado, I'll stop sharing my screen and I'll turn it over to you.

DR. BARBOSA: [3:56]

Judy, thank you for that introduction and what a pleasure and an honor it is to be with you all this evening. First of all, you're here. So you already know that NAAF is not only the leading organization that is patient facing for people experiencing alopecia areata, but it I want you to know it also is really one of the very best patient facing organizations in all of dermatology. So it's it's an honor to be here. OK, so here comes the first Test and that is can I share my screen properly? OK, how am I doing? OK, so next you heard Judy mention that I have been a speaker at the NAAF Conference. For those of you out there who I've already had a chance to

meet at the NAAF Conference, I want you to throw up an emoji so I know you're there. If I haven't met you yet, I hope that you put oh good, I see some hearts.

DR. BARBOSA: [5:00]

I want you to put the NAAF Conference on your calendar for 2027 because it is a conference that offers education, support, and fellowship like no other. OK, so let's get into it. I want you to put your questions in the chat as we go. I'm going to leave a lot of time for Q&A at the end. OK, so let's make sure we get your questions answered. OK, test #2 can I advance slides? Look at this, 2 for two. So you've already heard the introduction, I'm Vicki Barbosa. I'm an associate professor at the University of Chicago. Hair loss is really all I do now here in scalp disorders. When I started here a few years ago, it was 1/2 day a week. Now it's my whole clinical program. So I am really dedicated to treating people experiencing hair loss of all types. OK, so tonight we are going to really talk about alopecia areata in skin of color. Why this needs to be a conversation, right? Because hair texture, culture, and identity matters. Maybe even in a different way than in other populations. I want to have a conversation about treatment choices and expectations. As we look at some of the treatments that are available, there are some considerations that we wanna have really that sometimes revolve more around your confidence and trust in your dermatologist as well as in the medication option. So we'll talk about that a little bit and then I'm gonna also just give you some strategies on how to approach working with your dermatologist. And then again, we'll leave some time for questions. Hope that sounds good. So the first thing that I really think it's important to acknowledge is that hair is more than just hair. And that's particularly true, I believe, in people of color.

DR. BARBOSA: [7:07]

There is such a rich history of hair styling that dates back generations. There is the community that comes from going to the beauty salon, being in a chair for, you know, 4 hours, 6 hours, 8 hours, 10 hours, getting your hair braided. There's what it is to have your friend, your, you know, your sister, your mom help you with your takedown, right? There's a lot of time and effort and conversation that is dedicated to hair in our population. It's personal expression, it's creativity, it's concealing some areas. I'm seeing emojis. So I think what I'm saying is resonating with some of you, and what I want you to know is, first and foremost, it is OK to acknowledge that you're not OK if you have been diagnosed with alopecia areata. OK, We want to get you to being OK. But I think it is important to acknowledge that this can be a difficult diagnosis. If that resonates with you, throw up some emojis and I'm seeing a lot of them now. I don't want you wallowing and not being OK, but I want to acknowledge that any hair loss, whether it's one patch or a whole scalp is hair loss. And that is, I would imagine for some of you, scary, upsetting, maybe angering, but mostly scary, OK. And so I want you to know that it is OK to experience those feelings and then work through them, get to action, OK, just like every other part of life.

DR. BARBOSA: [9:01]

What I want you to know is I am so proud of NAAF for bringing the issue of alopecia areata and skin of color to the forefront, not only with this webinar, but also in sessions that we do at the annual meeting market calendars. Because alopecia areata is in fact more common in people of color. Did you know that we see it more commonly and it's sometimes presents differently, particularly in black patients. Hair loss can be more complicated because I expect that you may see some research coming out in publication soon, but we, you know, spoiler alert, but hair loss can be really complicated, right? So sometimes it's not just that you have alopecia areata, right? In skin of color traction alopecia is very common, right? That's the hair loss that occurs from our styling, particularly braided styles like individuals, cornrows, sew-ins, ETC, cetera, crochet styles or even just tight snatched back, laid edges, ponytails, right? Sometimes people have alopecia areata and also female pattern hair loss or male pattern hair loss. So alopecia areata can be made more diagnosis, can be made more complicated by people having multiple diagnosis, and sometimes it just gets misdiagnosed. OK. So it's really important that we're having this conversation so that you can be armed with the information you need when you go see your doc. So what is alopecia areata? Well, you guys are on this webinar, so that means you're already familiar with NAAF.

DR. BARBOSA: [11:01]

So you probably know this already, or you might, but alopecia areata is an autoimmune condition affecting the hair follicles. There are many different autoimmune diseases. Understanding them is complicated. Autoimmune diseases often run in families and usually it's not that all of the family members have the same disease. So, for instance, you might have alopecia areata, but you might have a aunt who has vitiligo or a

cousin who has lupus or, you know, a mom who has rheumatoid arthritis. There are lots of different autoimmune conditions. They have, you know, complicated genetics. They can be multifactorial. But autoimmune diseases do sometimes run in the family. That's a question I hear a lot in clinic. If I have alopecia areata, does that mean my children are going to have it also? The answer is no, it doesn't. But we also can't predict what's going to happen. If I could predict that future, I would also predict some Lotto numbers for myself. Just saying. Alopecia areata can involve the scalp, but it can also. Those hearts are for me winning lottery, OK. I'm still going to practice dermatology though, because it's still the best job in the world. OK, but I'll have better vacations. OK. So it can also involve facial hair, like the eyebrows or the eyelashes. And honestly, for some people, that's even harder to come to terms with because we rely often on facial hair to give our faces definition. It can involve the beard that tends to bother male presenting patients more than female presenting patients. And it can also involve body hair. One of the things that's important to know and is that the follicles remain intact for the most part and capable of regrowth. And I'll tell you honestly, what I have come to believe is that fact can sometimes make this roller coaster ride even a little steeper.

DR. BARBOSA: [13:17]

So what do I mean by that? Well, in the world of hair loss, they're really two big categories. There's hair loss where the follicles are still there, but maybe misbehaving like an alopecia areata. And there's hair loss where there's permanent damage to the follicles and the follicles are literally replaced by fibrosis or scar tissue. We call that scarring alopecia. And on the one hand, it can be very devastating to tell a patient that they have had permanent follicle loss and we can still treat them and sometimes have some regrowth. But there is some finality that comes with understanding that some of those follicles aren't coming back and then people can move on. And what I have found over the years with alopecia areata patients is that because those follicles are always there and always capable of regrowth. Many people, especially in the years preceding the JAK inhibitors, which we'll talk about in a minute, many patients have been on a very long roller coaster of regrowth, hope, joy, disappointment. As the as new patches develop, does that roller coaster resonate with anyone? If you've been on a bit of a roller coaster ride, throw up some emojis so I know you're out there. And so on the one hand, of course, we are happy that in alopecia areata, the follicles are still there, right? But I also want to acknowledge that leads to perpetual hope. But sometimes with that hope and dreams fulfilled, it's followed by a little disappointment if the condition flares again. And so I just want to acknowledge that's part of the ride sometimes. And for some people, that gets exhausting and some people with significant hair loss sometimes say, you know what, I'm just not going to worry about it anymore. I'd rather rock my bald self. And that's OK, too.

DR. BARBOSA: [15:15]

OK, You're the boss. So it's important to know that alopecia areata has different appearances. So I've shown you some pictures of one or more Oval or round, you know, patches that can occur anywhere on the scalp. However, it can occur on the whole scalp. We call that alopecia totalis. It can involve body hair, as I mentioned. We call that alopecia universe. Alice. That's that word soup that Judy was mentioning earlier. And it's really important to know that there can be a band like distribution. And the reason this is important for our conversation is that we see this pattern more commonly in black patients particularly. And this band like distribution is called ophiasis pattern, alopecia areata. Now I wish the chat were enabled in this moment because I would ask you guys, what does this look like to you? You can imagine that this band like pattern might get misdiagnosed and we'll talk about it in a SEC. But I also want to just acknowledge that while it's less common, there's also a diffuse pattern where there's there's hair loss throughout the scalp that also can get misdiagnosed as more of a stress shedding. We're going to come back to that ophiasis pattern of alopecia areata in just a few minutes, but I want you to keep that slide in mind. I'm going to show it to you again. Keep those photos in your mind. OK, my friends. OK, so does alopecia areata affect people of color differently? Yes, it can. Right.

DR. BARBOSA: [17:06]

So we've talked about the fact that it can be more common. I also want you to bear in mind that curly hair texture can conceal hair loss. That's a plus and a minus, right? So when you know you have hair loss and you've got curly hair, those curls can really help to camouflage the thin or alopecia patches. But sometimes those curly hairs, especially at the top or in the back, also mean you don't know there's a problem right away. So I've seen many patients who didn't even know they had their first patch of alopecia areata until they went to the hair stylist and the stylist said, hey, what's this been? They were like, what are you talking about? If that resonates with you, throw up an emoji for me. OK, If someone else diagnosed your alopecia before you even

look at that. Crazy, right? Someone else diagnosed it 'cause you didn't even know what was happening back there. Well, just know that your experience, you're not alone. As we said at the top of the hour. So the hair texture and your styling can help camouflage it, but it also might delay diagnosis. Styling We're going to talk about a little more in a moment, but it's really important that as you style to camouflage any alopecia patches that you're not doing more damage to your hair or your follicles through that styling. It's a bit of a catch 22. And as we started to talk about earlier, culture shapes your experience with hair loss. How many people grew up hearing that your hair is your crown and glory or your crowning glory? I've heard both. Does that resonate? Look at all the thumbs and hearts, right?

DR. BARBOSA: [19:01]

So it's like we are taught that it is our God-given, right? And it's right there in the Bible that's our crown and glory, right? So what does it mean if we don't have our hair? I would submit that your crown is on top of that head whether you have hair or not. But I think it's important to recognize that the value of hair is really very deeply rooted in our communities. And it is really important that we continue to work to shift how we value ourselves, how we define our beauty and our self worth and understand that none of that is appearance based and never was. So you remember the image I asked you to a few minutes ago about the ophiasis pattern alopecia areata? Well, this really drives home the point that sometimes the diagnosis is not clear. OK, ophiasis pattern alopecia areata is actually not that common, but what is super common is traction alopecia, particularly in black women or in people who wear locks or other braided styles. How many of you have actually heard of traction alopecia? Throw up some emojis. There we go. I see a lot of brown thumbs. I love it. OK, umm, there are other items on the differential. My goal tonight is not to give you a full differential diagnosis for alopecia areata. It's just to let you know that there are other diseases and oh guess what? The two pictures I'm showing here are not both traction alopecia. The top photo is traction alopecia. The patient below actually has a different condition called frontal fibrosing alopecia or FFA. That is a scarring alopecia. Unlike alopecia areata, traction is what we call biphasic.

DR. BARBOSA: [21:15]

So it starts out as non scarring and we can reverse it if we catch it early, but over time it becomes scarring. So as a dermatologist, it's really important for me and for others not to make assumptions when people come in the door, particularly if it's, you know, black women or people who wear tight buns or hairstyles. We can't assume it's traction alopecia, right? We really have to take our time to go down the list of differential to make sure that we are doing you, the patient, the proper service and giving you all the consideration that your unique case requires and deserves. So how do we as dermatologists make the diagnosis? Well, we take a good medical history, right? So you should expect that people are asking questions about your history and your family history. We of course, examine the scalp and your doc or your PA or NP, your, you know, physician or your healthcare provider should be during doing a thorough scalp exam and also should be looking. Now, we don't have to make a big deal of looking at your face because we're looking at your face when we're doing the history. But we're taking note of whether or not there's any eyebrow loss or eyelash loss or facial hair loss. And we will often get out a dermatoscope, which is a fancy name for a big, a magnifying glass with special superpowers. And that lets us look up close. We can't see the follicles below the surface, but there are a lot of clues that we can have at the surface when we look close enough. And using a dermatoscope to look at hair and scalp is often called trichoscopy.

DR. BARBOSA: [23:11]

So that's something that you will often see your dermatologist use as a tool to help with the diagnosis. And this is really important for you to hear. Most of the time, diagnosing alopecia areata is a clinical diagnosis. Most of the time, the history, the physical exam, and the trichoscopy give us the diagnosis and a biopsy is not needed. So I don't want you to feel like if you went to the doctor and you didn't get a biopsy that you were cheated because chances are you didn't need it. That actually raises a question. It's like I'll be you and me, I'll ask the question, then I'll answer it until we open up the Q&A. But the question you have in your mind, I'm guessing is, so how do I know if I need a biopsy or not, right. Well, again, that's really up to the dermatologist. But we biopsy when we are not sure, right. So if we are not sure if someone has traction or ophiasis pattern alopecia areata or FFA, we'll do a biopsy, right? If we are not sure if someone has diffuse alopecia areata or telogen effluvium, which is a bit of a stress shedding that comes from many different physical or emotional stressors, we'll do a biopsy. So it's not always a first step, but it's something that's in our hip pocket if needed. I want to say again that the emotional impact of this disease is real. I actually, I'm going to ask another couple of questions that you're going to answer with emojis.

DR. BARBOSA: [25:04]

How many of you have a dermatologist or healthcare provider that's helping you manage your alopecia areata? Great, and I want you to keep them going if you are happy with your dermatologist or healthcare provider and you feel that they are adequately addressing your emotional needs as well as your dermalogic needs. And let me be clear when I say that you know the dermatologist is not also a therapist, right? Is not also a hair stylist, but should certainly be able to point you toward resources. And again, you know, I encourage you all to turn to NAAF for things like education and support. The emotional impact is real because there is a lot of uncertainty about the progression, whether or not there's going to be regrowth, if there is regrowth, whether it's going to come out again. That's that roller coaster we talked about earlier. No matter what your racial or ethnic background is, whether you're a person of color or not, this can cause anxiety or even depression. It can shake your confidence. It can affect yourself, image and your self esteem, right? And we want you to work on that so you get those things right back. Not everyone feels rocked, but a lot of people do. This can impact your relationships at school, at work, dating, in social settings, at events, if on a windy day, right? And it's important to know, and I have seen this in clinic, that the size of the patch does not tell us the emotional impact. So I have seen people with small areas that are easy to conceal who are devastated by this diagnosis. I've also seen some people who have totalis or universalis who are like, you know what, I'm going to keep it moving. It is what it is.

DR. BARBOSA: [27:11]

So it's important to acknowledge and embrace the fact that your how you feel about this and how you manage it is does not have to be guided by the size of the patch. And let me tell you, what you also do not need to do is come into the doctor's office apologizing, right? So the number of times people feel embarrassed to come in, they say, oh, I feel this is vain, right? But it's bothering me. It's not vanity. This is a medical condition. It's a disease that merits treatment. OK. I want to acknowledge that there are a lot of questions to navigate when you're living with alopecia areata, and feel free to put some comments in the Q&A I do want to hear from you. I imagine that these are some of the questions that you navigate if it's especially if it's not easy to conceal. When do you tell people? If you tell people, how do you handle difficult personal situations like going to the gym and wanting to swim, right? Or like I said earlier, you've got a windy day. Are you worried about your scarf or your wig? How do you handle special occasions? You know, one of the things that's that I have learned, you know, it's actually interesting because particularly in skin of color communities, when you don't have alopecia, people tend to have a lot of fun with hairstyles, right? You know, you saw me in the picture before I had braids. I cut my hair off. Now it's short. You know, maybe it's in a sewing next month, right? It's it's different every time. I have patients and friends who have wig collections. Sometimes the wigs have names, right? Sometimes you feel short and sassy. Sometimes you feel long and glamorous, right? And all of that is fine and good when it's for fun. But what I have learned from my patients and throw up some emojis, if this resonates with you, is that fun that we have with hairstyle shifts when it's no longer for fun, right? Wigs are fun when you're you're just, you know, wanting to have a date night. Oh, look at that. But when suddenly it feels like it's not a choice anymore. There's nothing sassy about the short wig and nothing glamorous about the long wig. And I want to acknowledge that there are questions that you get from friends, from colleagues, from strangers. I've still to this day, this is probably 15 lowered, maybe 20, let's just say 15 years ago, I was really struck with a young patient of mine who I'd see, who had universalis. And she was, you know, maybe 10 or 12. And she came in one day and I'd always ask how was school? And she told me she had just got in detention. And I'm like, what? You know, you're too smart to be in detention.

DR. BARBOSA: [30:17]

What happened? And then a classmate teased her about having cancer on the playground and she sucked them, which is wrong, right? But, you know, it's also wrong to tease children. So, you know, children can be cruel, but sometimes adults aren't much better. And some questions are out of curiosity, and sometimes they're just rude. And I am guessing that many of you have experienced that, you know, And then there's the question, are you going to conceal it or not? So, for instance, the patient you're seeing in this picture is actually a woman and has one of the most beautiful faces. I mean, just mesmerizingly beautiful. And she's like, this is what it is. Sometimes there's hair, sometimes there's not. Like it is what it is. And some of my patients decide to embrace being without hair. Like I said, it's all good. What matters is our trying to help you achieve your goals. So can alopecia areata be treated? Yes, it can. Now we all know that there's not a cure yet, but there are treatments and the treatments available depend on how much of your scalp is involved, your age, your medical history, and your goals, right? There is no magic bullet. Oh, and sometimes you know, we do no

treatment at all and a patch or two will come back on their own. But for people who have larger areas involved and are undergoing treatment, it can take months to get where you want to be and it's always possible to relapse even if you're on the best of treatment regimens.

DR. BARBOSA: [32:11]

So there are many treatment choices available and we all know I think that the landscape has changed in the last few years. So some of the mainstays of treatment right now include steroids, which can either be topical steroids and or injected steroids. I tend to limit steroid injections to and offer them to people who have fewer areas of involvement because I always say it's not fun but it's fast but they are painful. It's a small needle and it's quick, but it's multiple injections usually, so it's not like we're going to take someone who's lost 50% of their hair or has a SALT 50 and inject half of the scalp, right? Topical steroids are sometimes used in alone or in conjunction with injected steroids. We've been using a lot of minoxidil in the last few years to support regrowth. For smaller areas of involvement, we might suggest topical 5% minoxidil. For larger areas, we are often recommending oral minoxidil, which was originally used as a medicine to lower blood pressure, but we can use it in doses so low that they don't normally impact the blood pressure and, you know, still have some good response with regrowth. Fortunately, our newer options have made other things like stronger immunosuppressive oral medications or contact immunotherapy, which was not super effective, things that we don't use quite as much anymore. And of course, now everyone's talking about the JAK inhibitors. Have you guys heard about JAK inhibitors? Throw up some emojis for me. If you've already heard about JAK inhibitors. Great.

DR. BARBOSA: [34:06]

Now here's one of the things that's really interesting for me. So I'm located on the South side of Chicago and I take care of a lot of a very diverse patient population and a lot of people of color. And it's really interesting when I am with my colleagues who are like, you know, everybody's coming and asking for the JAK inhibitors, My patients who are largely people of color who tend to be more risk averse in my estimation and a little more like, I don't know, how long has it been around? What are the longer, what's it going to do? I don't know. You know, it takes a little more time for people just to do research and decide that they're ready. And I want you to know that's OK too. It is true that the sooner we start some of these medicines, the more likely we are to have treatment success. But I think it is very important that patients not feel pressured into medicines that they are not quite ready to try. OK, so JAK inhibitors are amazing. I will tell you that they kind of interrupt the signal involved in the autoimmune kind of attack on the follicle. Right now there are three FDA approved medications, baricitinib, ritlecitinib and deuruxolitinib and that is amazing that we have three choices and spoiler alert, there's a fourth one coming down the pipe that we're expecting next year. They all work. They don't all work quite equally well for each person and we don't have a great way to know which one is going to be best for which person. So we will often start with one and after a year usually there's treatment success, but if not, we may switch. It's important to know that ritlecitinib came out with FDA approval for children 12 and over a few years ago. Baricitinib has recently attained FDA approval for 12 and over as well.

DR. BARBOSA: [36:13]

So now we have some nice FDA approved choices for children 12 and over. It is important that you have a conversation with your dermatologist about the risks and benefits of these medications. While the risks are low and treatment response is high, they are not without risk. And it's important to kind of have that conversation and be comfortable, as I said, and know that regrowth can take easily six months to a year. This is one of many patients I have had who have, you know, and this is a gentleman. The other you're looking at the right side of his head, the left look exactly the same. So had lost over half of his hair and now has complete regrowth. I actually just saw him again a couple weeks ago. These medications do require blood work, monitoring and again, you know, close contact with your physician. It's important to know that sometimes initial regrowth, the hairs might be finer. They might be without pigment but use or even have a different texture. But that usually reverts back to your normal texture. And I can tell you that I, as a dermatologist, take photographs at every visit because it is very hard to keep track of what's going on. You know, wet patches are getting better, which are worse. I don't want you guys to feel like you have to have, you know, an obsession of taking your own photos. I think that can get to be unhealthy. So I don't want you to overdo it. But it's something as a treating physician that I do. So in the last few minutes before we cut to the Q&A. So get your, if you're, if you've been holding on to your questions, start putting them in the Q&A now. I want you to be prepared for your dermatology visit, OK, Especially if it's your first time meeting a doc. You have any medical

records available that you can have available? And I know sometimes they're not available. It's not the end of the world, but the more information you can provide, the better, OK.

DR. BARBOSA: [38:17]

If you've had recent blood work, that can be helpful. Certainly if you have had a biopsy for some reason, that would be helpful to provide as well. Now when you bring that, the physician may not review if you bring a telephone book size medical record. We may not always look at that right in the 15 minute visit, but we will look at it at the end of the morning or at the end of the day. It's really important, perhaps even more important to bring a list of your current treatments for the alopecia, not only the medication, but the dose you're on. Helpful to know what you've tried in the past that may or may not have worked. And obviously we also want to know about your medical history and other medications that you're on. You probably have questions, you've probably done a lot of research. Write your questions down. Please know that we may not be able to get to all of your questions in one visit. But the ideal relationship between a patient and a doctor or care for provider is a long term relationship. So over time your question should be answered and ask your dermatologist about local resources for support. So for and support not just in terms of emotional support groups. But hey, are there people you can recommend who do you know, microblading or micro shading for brows, you know, is there someone that you know, fill in the blank who's good at doing custom wigs, right? To help me camouflage this? Hopefully you know if you have a dermatologist who sees a lot of hair loss patients, they'll have resources that they can direct you to. Partner with your dermatologist, make sure they understand how is how this is impacting you.

DR. BARBOSA: [40:07]

If for you it's kind of a no biggie, but you're just here for your injections and you got to go, cool. If this is, you know, getting you to the point that it's hard to leave the house, we need to know that so we can refer you to a therapist, OK? Share your styling practices. They should be asking about those. Share your goals. We kind of know the goals, you know, get the hair back, We know that part, but you know, more specifically. And then if there are some barriers to you're getting treatment, if medications aren't covered or they're too expensive or even if just getting to the doctor is costly and difficult or you're coming from a really long way, tell us that OK, So that we can make a plan that works. And then you should be comfortable with your treatment plan and with the time frame for reassessment. And I'll be honest, I don't see people back right away because regrowth takes a long time, so it might be months. Make sure that when you care for your hair and scalp, you are gentle cleansing, no traction inducing styles. We don't need to give you a people a second diagnosis. So really limited use of braids. If you're wearing braids, they need to be knotless. You need to be out of braids more than you're in braids. You want to be careful about elastic. For instance, ponytail holder, you know, even wig grips, you know, you want to be careful at the edges. And bear in mind we love holistic treatments as communities of color and I support them. But you have to know that oils and supplements are not adequate treatment for autoimmune disease. Now, some of my patients say I want to try this first and I say, OK, right, as long as I have explained the risks of delaying treatment. But I always joke, you know, I'm not saving any lives in hair loss clinics.

DR. BARBOSA: [42:04]

So you do want a physician or practitioner who's going to respect your desires on how to move forward. But I'm just telling you, scientifically, you know, supplements are probably not going to be enough to do the trick. But sometimes, you know, especially with smaller patches, fewer patches, sometimes AA reverses on its own. In fact, it often does. And then sometimes the Rosemary oil gets the credit. The decision of whether or not to style, how to style, or whether or not to camouflage is your personal choice. We talked about that a little bit earlier. There are lots of options for wigs, for toppers, for custom hair pieces. You can use scarves, head wraps, hats. I love hair fibers for concealing those keratin fibers for concealing smaller areas. There's, you know, eyebrow makeup. There's the, there are even little eyebrow wigs, very cool. I learned about those actually at the last NAAF meeting. And then there's micro blading or micro shading. So ask your dermatologist. Are they sure this is alopecia areata? They're probably short, but ask might I have more than one condition? You can screenshot this if you need to. How severe is this? And is it severe enough that I qualify to consider a JAK inhibitors as a treatment? Have we considered my goals and my health history as we lay out this treatment plan? And what should I expect and hope for and how are we going to assess results? I think these are 5 critical questions. I just want to end with resources. Obviously, NAAF is a number one and we've talked about that a lot. If you have some resources that you love, I want you to just put them in the Q&A so we can share those out with folks. I also want you to know that if you don't have a dermatologist who is facile with managing

people with skin of color, you can find a dermatologist through the skin of color societies find a doctor page. I also want to make note that the American Hair Research Society is doing an amazing job of putting forth and encouraging research in alopecia areata and all forms of hair loss. And they have some patient information on their website, but again, that has the most comprehensive information for you.

DR. BARBOSA: [44:32]

So with that, I am going to pause. I'm going to thank you for your attention and I'm going to take some questions.

JUDY WILLIAMS: [44:40]

Thank you, Dr. Barbosa. I'm going to introduce George Gondo. He's NAAF Chief Mission Officer. He will be moderating the questions.

GEORGE GONDO: [44:50]

All right, thank you, Judy. Thank you, Dr. Barbosa. There's some really great questions in here. There's one I want to start off with because it was related to what you wrapped up with Dr. Barbosa. And this is a question related to wearing a weave when you have alopecia areata. Would you recommend wearing a weave or do you not recommend wearing a weave?

DR. BARBOSA: [45:13]

That's a great question. So first I want to divide the weaves into sew-ins and glued on. OK. And I can tell you that I never I'm in favor of gluing tracks on to the scalp because when people go to remove those quick weaves, hair comes off with the glue. OK, now whether or not Now I'm never gonna recommend a sew in, but how I feel about them really depends on whether or not you are prone to traction alopecia. So I often joke that life ain't fair right? And some people can wear sew-ins 13 months out of the year and never have a problem and have their edges perfectly intact. And for some people even one or two weaves is enough for that front hairline to start to creep back and give you edges problems. So what I would say is if you are not prone to traction alopecia and you want to wear a sewing, that's fine. If you have a patch of alopecia that requires you to use some topical treatments like topical steroids or and or topical minoxidil, You might want to for instance not use a cap so that you and just have the tracks sewn directly onto the braids so that you can still access your scalp to get the medicine in between the tracks. If you are prone to traction alopecia, if your edges are not where they used to be, then you might want to limit your sew-ins.

GEORGE GONDO: [46:52]

Great. Thank you so much. A couple other questions here. There are a number of questions around different types of corticosteroids which you touched on in your presentation. First, do you recommend, let me find the question here real quick. Do you recommend those used long term or is that something that is a good long term strategy? Do you typically require subsequent treatments and how do you maintain those results? Some other questions around seasonality of reoccurrence of hair loss when treating with corticosteroids and if there might be something that's related to, you know what might be the cause of that.

DR. BARBOSA: [47:49]

So those are really great questions. So let's first talk about what I think the foundation of the question is, and that is the potential risk of topical or injected steroids. So as you may know, steroids are used to reduce inflammation. They're one of the best medicines to do so, if not the best. But over time, either topical or injected steroids have the run the risk of thinning the skin. We call it atrophy. So any person who is receiving topical or injected steroids, the physician or healthcare provider should be monitoring for early signs of atrophy and shouldn't just be continuing to inject or write prescriptions without monitoring. That's something that might be hard for you to do. You can't see your scalp, but we can, right? So what I would say is this, we treat the spots that need treating and for many people with alopecia areata, those spots rotate around.

DR. BARBOSA: [49:00]

So it's not like over the course of a year or a decade or a lifetime, you're putting the steroids in the same place all the time, right? That's actually different for some other forms of alopecia, right? So what I would say is, are some people on topical or injected steroids long term? Yes. Is that something that requires monitoring? Yes, It's again in alopecia areatas, it's often that it's different spots. So the risk is decreased compared to someone for instance with CCCA where that spot is there for life. So it requires monitoring in terms of seasonality. What

I would say is that's kind of a different issue. The what we see most commonly as a seasonal shed is what we call telogen effluvium. And there are people who have a spring shed or a fall shed particularly, and that hair usually comes back on its own. And the secret is that there really isn't a treatment that helps it come back faster, but it does come back.

GEORGE GONDO: [50:11]

Thank you. Switching gears real quick, we've had a couple questions related to different strategies around camouflaging. One asking what how do you feel about cranial prostheses and wigs? And another question around when is it time to start thinking about altering your hairstyle in order to mask the patches of hair loss?

DR. BARBOSA: [50:37]

So these are great questions. How I feel about cranial prostheses or wigs is really based on how you feel about them, right? So for people who are have who have a lot of hair loss and it's hard to conceal and they prefer to conceal it, I think they're a great option. I want to be clear that cranial prosthesis is kind of a medical term for wig. And I want to make you aware that sometimes insurance will cover wigs. And so it's you can call your insurance company and ask. They will often ask you for your diagnosis code and that is something that your physician can provide to you so that you can find out whether it's covered or not. And sometimes they require that you go to someone who's certified to provide medical cranial prosthesis. And sometimes they just have you mail in a receipt. So that's worth investigating because a good wig is expensive. So I feel like they are a great option if they help you feel better about how you show up in the world.

GEORGE GONDO: [51:50]

Now, George, I need you to remind me of the second question again. Oh, the second part of it was just around when is it time to start talking about changing your hairstyle to mask the hair patches of hair loss.

DR. BARBOSA: [52:02]

Thank you for that. And the answer is once again that it's time to have that conversation when you feel like it's time to have that conversation. If you are wanting to camouflage the hair loss and don't know how, that's a great conversation to start with your dermatologist.

GEORGE GONDO: [52:25]

It's also a great conversation to have with a skilled hair stylist right now going back to treatments, lots of questions in the Q&A around JAK inhibitors, some related to whether someone could be a candidate for JAK inhibitors with different types of Co occurring conditions, some around being a candidate for JAK inhibitors with a longer duration of alopecia areata. And then the other some questions around whether JAK inhibitors would be effective for androgenetic hair loss.

DR. BARBOSA: [53:10]

OK. So I'm just going to pick that first one off, that last one off 1st and that is this. I do not foresee that we are going to be using JAK inhibitors for androgenic alopecia also known as male or female pattern hair loss anytime soon. I think the risk profile doesn't justify it and nor there are there any studies justifying that. OK. So for alopecia areata and kind of appropriateness for you, there are a lot of things to consider. It's kind of complicated. So part of it is your history, right? So somebody asked about duration and what that really gets at is the fact that data shows us that our best chance at obtaining regrowth is when we start to treat early with the JAK inhibitors. But I want to say loud and clear that has not stopped me. Duration has not stopped me for trying with from trying the JAK inhibitors in patients who have been without hair for 5/10/15 twenty years. And I will tell you that I have several patients who've had their alopecia areata for a very long time who now have full heads of hair. Honest to goodness, it's literally miraculous. Now, here's the hard part. Most of my patients who have had alopecia areata for that long, for 10 years, 15 years, 20 years, have already made peace with it. They've moved on. You know, they wear a wig or don't wear a wig like they are like I'm done the I'm off the roller coaster. And the hard thing for my patients is to decide to get back on that roller coaster one more time. That's a big decision when now you've embraced your alopecia, you know, as part of your identity, right? And the, and you've moved on. And I want to acknowledge that's hard, right?

DR. BARBOSA: [55:04]

So yes, it is still worth a trial a try if emotionally it makes sense for you and also understanding that it might work, but it might not. And that can be disappointing in terms of appropriateness. We're looking at your age,

we're looking at how much usually insurance really wants 50% or more hair loss. We do know that facial hair loss can enhance the perception of severity. So we look at that too. Medical history, things like history of blood clots, you know, history of heart disease, there's all kinds of things that we're, we're looking at as we make our determination. And there is blood work that we follow, which might vary a little bit depending on which JAK inhibitors we choose. But it's, it's really pretty complicated and the, so it's an individual conversation, but the results have been almost unbelievable.

GEORGE GONDO: [56:10]

Great. Thank you. There's a couple of been a couple of questions around over the counter treatments. Have you seen any over the counter treatments be effective in particular things like those laser scalp or the red light scalp masks? And is there anything else that you think may or may not be successful in regrowing Heron alopecia areata that is available over the counter?

DR. BARBOSA: [56:39]

That's a great question. So there are lots of treatments for hair loss that are available over the counter, right? Things like topical minoxidil available over the counter, things like hair growth supplements over the counter, things like red light laser caps or photobiomodulation devices, right? And here's the thing, all of those have really been evaluated for male or female pattern hair loss or androgenic alopecia, right? There's not a lot of data supporting their use in alopecia areata. Now that said, these are things that are not going to hurt you, right? So if it is your choice to try one of these things first before medical treatment or in conjunction with medical treatment, I don't have a problem with that. I really don't. Do I think they are very helpful? No, I don't. But again, not going to hurt you. And I also want to give a nod. And I think I said this earlier to the fact that particularly when people have one or just a few patches that come and go, which is really what many people's experiences with alopecia areata, even if we do nothing, it's going to come back on its own anyway. So is it the supplements or is it just good fortune and science that we don't understand well yet? Hard to say.

GEORGE GONDO: [58:07]

Thank you. Opposed. I think we have time for one more question. Great. I'm gonna. I'm gonna. I there's one in here I wanted to ask and I'll look. I got to find it real quick. OK. Last question, you talked about the emotional toll and a social toll that alopecia areata can have on someone. What can family and friends do to help someone experiencing care loss feel supported without pressuring them about their appearance?

DR. BARBOSA: [58:33]

That is a great question and the answer is it probably depends on the loved one you're supporting because people process this differently and people need different things. Some people need a listening ear and just to talk about it. They don't need fixing. They just need you know someone by their side to say I understand or I'm trying to understand or I'm here to support you. So I think the short answer is the very best thing you can do is ask, how can I support you? And that might mean going with a friend or a loved one to the NAAF meeting or to a support group meeting. It might mean, you know, just being a shoulder to cry on because someone's having a down day, even if they are OK. Overall, the best thing you can do is ask. I know we're out of time. I want to thank you so much, NAAF, for allowing me this space to connect with people, even if it's by thumbs up and heart emojis. I want to say to all of you out there, even though I can't see your faces, I do see you. And I really hope that I see you at the next NAAF conference and you come up and give me a hug, OK? If you're a hugger, I'm a hugger. If you're not a hugger, you could just say hi.

JUDY WILLIAMS: [59:55]

Thank you, Dr. Barbosa, and our sincere thanks to you for such a great presentation and for sharing your expertise today. We're grateful for your dedication and commitment to improving the lives of those living with alopecia areata. And to our audience, thank you for joining us. Please remember to share your feedback on today's webinar and help us plan future presentations. A link to a short survey will pop up in your browser window at the end of the webinar. Your feedback is truly appreciated. We encourage you to stay in regular touch with NAAF. Use the QR code here to subscribe to our e-mail list for regular updates on Alopecia, Ariada news and research, the monthly NAAF electronic newsletter, and notices about upcoming webinars and other programs like our annual conference that Dr. Barbosa has been mentioning. And to learn more about NAAF and the resources we offer, please visit naaf.org or e-mail us at support@naaf.org. This concludes today's webinar program. Thank you again for joining us. We look forward to seeing you in the next webinar.