NAAF Webinar Transcript: What's New in Pediatric Alopecia Areata (January 2023)
Dr. Britt Craiglow
LISA ANDERSON, PHD: (00:00)
Welcome everyone. Welcome to the National Alopecia Areata Foundation's webinar, What's New in Pediatric Alopecia Areata Treatment. Joining us today is pediatric dermatologist Dr. Britt Craiglow associate professor adjunct in the Department of Dermatology at the Yale School of Medicine. And I'm Lisa Anderson, senior director of research for NAAF

Before we start the webinar, I'd like to cover a few housekeeping details. We've disabled chat for this webinar session. Please post questions for Dr. Craiglow in the Q &A section. Please keep your questions general for the benefit of all audience members. This webinar is being recorded and all registrants will receive a link to that recording via email sometime tomorrow. And finally, please share your feedback with us.

At the conclusion of the webinar, a link to a short survey will pop up in your browser window. Please complete the survey there.

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 and company, Pfizer and Sun Pharma.

Before we start today's webinar, I'd like to tell you a bit about NAAF and our mission. The National Alopecia Areata Foundation is the leading advocacy organization for alopecia areata. NAAF's mission is to support research to find a cure or acceptable treatment for alopecia areata, support those with the disease, and educate the public about alopecia areata. NAAF's vision is an empowered community with a choice to embrace or live free of alopecia areata.

To learn more about NAAF support resources and research and advocacy activities or to join us as an advocate or supporter, please visit our website at naf.org.

And now onto today's webinar, What's New in Pediatric Alopecia Areata Treatment. We're excited to have Dr. Britt Craiglow with us here today to kick off the webinar series for this year. Dr. Craiglow is double board certified in dermatology and pediatric dermatology. She sees patients in her private practice in Connecticut and also holds an appointment at the Yale School of Medicine as associate professor adjunct of dermatology.

Dr. Craiglow is a widely recognized expert in pediatric, sorry, pediatric dermatology with over 60 publications in major medical journals. She's a pioneer in the use of Janus kinase inhibitors for the treatment of alopecia areata. And she has a particular interest in health related quality of life. And she's a strong advocate for the advancement of new therapies for

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alopecia areata. I think it's fair to say that thanks to her work, there's a lot of new hope in the community for effective treatments for alopecia areata.

Dr. Craiglow, thank you so much for being here today. I'm going to stop sharing now and I will turn it over to you.

BRITT CRAIGLOW, MD: (02:55)
Awesome. Thank you so much. Okay. Hopefully this works. Hi everybody. I was saying to leave the last time we did this apparently was October of 2022. And I was like, as usual, racing around and trying to get my kids set up so they didn't bother me. And, and then, and then this last year since that was done, I keep having people, ~ I saw your video on YouTube.

And I'm like, what video? And so apparently this was recorded and put on YouTube. So now I have this like a little bit of stress. Like I have to do a good job because this is going to be in the world like forever and ever. So anyway, here I am. Thank you all for joining. It's really cool that you're on here like on a weeknight. If you're lucky, maybe you'll get to miss bedtime, but hopefully you'll learn something and we will have some time for questions at the end. So.

I always do this before talks to some disclosures. I have worked with a number of companies who have medicines either approved or in development for alopecia areata And I will talk about off-label use of medications because right now we really only have one on-label medicine for alopecia areata in kids and that's only in patients 12 and up. So most of my life is spent doing off-label treatment.

Before we kind of, the beginning, we're going to kind of just talk a little bit about alopecia areata, and then we'll really get into treatment because I think that's what most people want to hear about. And it's really exciting, actually. Like, there's a lot happening. I view this as a treatable disease now, and that's really different from the way we felt, you know, even five years ago. So it's a really, it's a great time, and it's just going to get better. So one thing I just want to cover really quickly is

that I often have people say, even just today actually, had a mom say, so does she have alopecia totalis? Or one time I was talking and I kept saying, ~ alopecia areata, and a parent said, you know, I don't want to, I just don't want to interrupt, but you keep saying alopecia areata, but he has alopecia universalis. And so let's just kind of define these terms. And for me, they're all the same thing. Okay. This is just a spectrum of disease and actually

We wrote a paper, I don't know, couple of years ago saying, like, let's move away from these terms, alopecia totalis and alopecia universalis, because even among dermatologists, we don't necessarily exactly agree on these definitions. Historically, alopecia totalis has meant complete loss of scalp hair, whereas universalis is complete loss of all hair all over the body. But if someone has one eyebrow and a few eyelashes remaining, does that mean?

They don't have alopecia universalis universal, so you kind of get the point. This is all the same disease. It's just a big spectrum of severity. So when a medicine is approved for

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alopecia universalis areata, it's approved for totalis universalis et cetera. So hopefully that's helpful. And many of you probably already knew that, but just that's a question I get not infrequently. And this kind of shows the spectrum. This is a very heterogeneous disease. No patient looks like another patient.

mild patchy disease. It can be one tiny little patch. It can be lots of patches. The patches can get bigger and kind of coalesce. And then of course, you know, on the other end of the spectrum, we can have complete loss of all hair all over the body. But a couple of other photos here I have like on the upper right, these are patients with more of what we historically called diffuse alopecia areata. So this is kind of this generalized thinning. I actually

think that this is probably more common than we think, especially when it's really subtle. So this is definitely on the spectrum. And then the bottom left corner is what we call Ophiasis pattern. That is still a term that I do use, even though it is all alopecia areata And this is where you have sort of a band-like distribution involving ~ up above the ears and then back around to the nape of the neck. And this

patient next to it has what we call sisypho, which is basically the opposite of Ophiasis So you have preservation of the hair back there and then loss of the hair on the top of the scalp. And we can have people who have patches and Ophiasis. You can have involvement of eyebrows and eyelashes and all of your scalp hair, or maybe just a little of your scalp hair. It's very, very different. unless you have complete loss, everybody sort of has a different presentation. And I think

One thing that's really, really hard about it is that it's so unpredictable, right? So you can have a patch or two and that could be all you get ever, right? Or it could go away and then a few years later you could have patches again or it can accelerate really quickly and then all of a sudden, you you or your child has no hair a few weeks later and a month ago you never even heard of the disease, right? So I think that the kind of waxing and waning and unpredictable nature of it is really...

tricky thing. if any of you are my patients, you know, I, often kind of talk a lot about the experience of alopecia areata. And I think, you know, probably most of you on here are parents. And I just want to say that you're, this is a very unique experience as, as a patient, but also as a parent. ~ and I think, you know, I always tell people, however you feel about it is okay.

Right? And yes, there are some people who are able to embrace it and cope really well. And sometimes it becomes kind of a defining feature. And that's amazing for those people. But on the flip side, I would say the majority of people, this is a really hard thing. And that's normal. OK? So I think a lot of parents come in and they sort of feel bad that they feel bad because people have said,

well, at she's not sick or at least he doesn't have cancer or, you know, why don't you try gluten free or maybe you should change your detergent or like, you know, everybody's kind of giving you their free advice all the time. And those things, you know, the person doing

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that is trying to be helpful, but ultimately it's really unhelpful. Like when you're having a hard time, you kind of just need someone to be there and not feeling with you. But people just don't get it.

just don't get it. don't, and I always tell families like, I don't actually get it in the same exact way you do or your child does, but I'm close because I've seen it over and over again, but it really isn't just hair. Okay. We would never say that about another autoimmune disease, know, like juvenile arthritis. Well, it's just your joints, you know, diabetes. it's just your blood sugar. Like give me a break, right? This is an autoimmune disease, just like anything else. And the experience of it can be lonely and difficult and hard to navigate. And I think it's important to

understand that you're not alone and it's OK to feel bad or be angry or sad or however you feel about it. And so the big question is always like, why did this happen? And I think I see a lot of people who come in and there's sort of this story about how the alopecia started. So a month before we took a trip or

three months before he had a vaccine or six months before we moved or there was a stressor a year ago, right? Or the day it happened, he ate X, Y, or Z, right? And I think it's totally human nature to sort of want to blame this on something or to assign blame to an event or some sort of environmental thing that happened. And I would say, know, like if my kids got it,

even though I sort of know, I would still probably be like, maybe it's this or maybe it's that, you know, but we don't know why really. We don't know why it happens when it happens. We know that you have to have this genetic predisposition, right? But it's not all genetics because even if you look at identical twins, the chance if one has it that the other one has, it's only about 55%. So I've seen identical twins where both have severe disease and I've seen identical twins where one person has very mild disease and the other

has complete hair loss. So it's of genetics plus, which is the same for a lot of things. And I think from what we understand now, at least, and this could for sure change, and maybe in five years I'll say, well, that was really silly what I was saying, and go take that YouTube video down. But at least from what we understand now, there really isn't something in the environment that you could change or modify to make this different. So I often say to families, like,

I get it, and sort of wanting to have a reason or an answer is really normal. But you can spend a lot of mental energy on that. And ultimately, you're never going to get it. And so if you can, even though it's hard, try to move away from, why did this happen? And instead, move towards, OK, what are we going to do about it? Or how are we going to treat it, if you're going to treat it at all? But these sort of triggers, we really don't understand them well. Personally, I think they're kind of

They're different for everybody. They're probably multifactorial, but it's still like a big areata that we don't understand. And so one, and I like analogies in my clinic and I'm really excited about some of the animation I did by the way here. learned, I was like, I need to make some

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new slides. So I did all these like fun things with PowerPoint. Anyway, so I like analogies and one that I use is that alopecia areata is like,

having to wear glasses, right? So I said, if family was like, pretend you brought Sally in and I'm an eye doctor and I examined her eyes. And I was like, well, she needs glasses, right? And this is the case in my family. My nine-year-old can barely see. he, we went to a well child visit a couple of years ago and he couldn't even read like the second line of the eye chart. ~ know, last year his vision was fine. All of sudden he needs glasses. Why? I don't know. I didn't need glasses when I was a kid. My husband didn't either.

his brother doesn't, it's just kind of like a thing that happens, right? And this is the same for all these diseases that you saw very nicely show up in the background here, but these are all autoimmune diseases too. They just happen, they just show up. And we know that there are these, you know, genetic things that kind of predispose us, but why do some kids get type one diabetes? Why do people have celiac disease? It's all kind of the same thing. It's just sort of a thing that happens. And so I think kind of viewing alopecia areata with that lens.

pun intended, is maybe helpful and can kind of help people move on from this sort of like, why I need to know why, and I'm going to change the diet, and I'm going to do this, and we're going to move, and we're going to, you know, because probably none of those things, unfortunately, you know, is going to help. So for those of you on here who have maybe a child who's recently diagnosed or even people who are, you know, a lot of times there will be a child who's

been really comfortable in their current school environment. And then maybe they're in preschool and they go to kindergarten or they move or something. I think everybody feels differently about how much or little that they want to share. And for sure, when disease is mild and it's not something that maybe you'd be able to tell that someone else could tell that your child has, then I think you

it's probably less important to decide what you want to say about it. But I think in the case of more severe disease, when it's more obvious to somebody else, think if you're able to be kind of proactive, I think is really useful. And that can be hard to do. But the thing is that by nature, humans are curious, right? And they want to know. And oftentimes, especially in severe disease, they're concerned.

All of you who have a child who has no hair, somebody has thought that they have cancer. And that's, by the way, a really hard experience and complicated. I think if you're able to say, either with an email at home or have the teacher, like, hey, Sally's new. She has something called alopecia areata. She's not sick. If you have any questions, please ask me, not her, that kind of thing. And NAAF has a lot of great resources for this.

And again, everybody has kind of a different comfort level. But I think at least you want the teacher, principal, like sort of support staff at school to know about it. And there are also things that you can do. You can have a 504 plan if your child wants to wear a hat in school. Like they can be allowed to do that, right? So kind of be your child advocate and decide what you want to say. And I think it can be helpful to kind of sort of

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prevent this unwanted attention that happens a lot. ~ think that's kind of what a big thing about severe alopecia areata. You get a lot of unwanted attention. We just kind of want to go to the grocery store and not have somebody look at us a little bit longer or ask us a question or say that they're praying for us. You want to be anonymous if you want to be anonymous. Or if you go to the playground, you just want to play and you don't want to have a child say, why don't you have hair?

And when kids are little, it's really mostly just curiosity. And it's coming from, you know, it's not coming from an unkind place, but it still doesn't feel good to be called . And, you know, I think as kids get older, unfortunately, some of them can be unkind. And I think that's another place where, you know, you have to be an advocate. And if something is happening at school that is not okay, like that's not okay. And you need to have a meeting and, you know,

Children need to feel safe where they are and not in a place where, you know, they're, they're uncomfortable. So, and I think in, in tweens and teens, a lot of kids may want to, you know, wear a hat or a wig and, and kind of keep their alopecia private, which I think is totally, totally fine and appropriate. But I will say that sometimes just having one or two friends who know that you can share with can be really helpful because this

feeling like you're kind of hiding all the time can be, you know, can be really tough. And this is something I talk about a lot with patients is I often say to kids like, does anybody ever ask you, you know, about your alopecia? and, know, sometimes they say yes. And sometimes when they're younger, they say no. And, but most of them say yes. And I then I'll say, so,

do you have, what do you say, you know, when they ask you and a lot of times the kids don't have an answer and they get a little bit uncomfortable and they kind of look at the floor and you understand that. Cause again, that's just unwanted attention. You don't want the question, right? But I think again, sort of being prepared is useful because that situation never feels good and it's nothing is ever going to make it feel good. But if you're ready for the question and sort of have a response, it's kind of there, then it's easier. It doesn't maybe ruin your day. It doesn't feel.

But you can kind of move on from it quickly. this is this, I have the website at the bottom. This is called Changing Faces. It's this really nice organization of the UK. And basically, their whole thing is just about visible difference. So lots of different conditions that are marked by visible difference. And they have resources. And this is sort of their recipe for addressing questions. And it's basically like, you explain, you reassure.

And then you redirect. So you move on. And usually what I say is like, decide what you want to say. And every kid is different. And some want to say more. And some want to say less. And I have kids with other visible differences that have gone so far as to make cards. And they'll give it to somebody to go learn more about what I have. But that's not common, right? But just kind of decide. And sometimes kids will say, I have alopecia. Like, I'm allergic to my hair. That's something that peers can kind of understand sometimes. And I'm not sick.

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And then quick move on, like, did you do the math homework? Or what are you going to do tonight? Or I like your new sneakers, whatever. And they kind of practice it and rehearse it. And then they're sort of ready when that question happens. OK, so that's kind of like the touchy-feely stuff. But I'm a pediatric dermatologist, so that is really all near and dear to my heart. if you have more questions about those things, definitely let me know. But I think really importantly, like,

However you feel is okay. you, like your feelings should be validated. And this as a parent is very complicated and difficult. And I think, you know, connecting with other parents, like through NAV or, you know, other ways, actually some of my patients even have connected, which is really cool. It can be really helpful just to have somebody else who has this shared experience and even just to have a text like, God, like I'm at the playground and.

somebody's looking at Johnny and I feel crummy about it. That's nice to have someone on the other end to get to it. Because you know your other friends, as much as they want to, they don't. OK, so talking about treatment, which is what we're here for. So there's a lot happening in treatment for alopecia areata. I said at the beginning, I really do view this as a largely treatable disease, which is really cool. Five, 10 years ago when I saw a new patient,

especially a young child, if they had severe disease, it was like my worst moments as a physician. Like, I'm a fixer. Like, I want to tell you, like, there's something we can do about this. that discussion was really often just kind of, well, you know, there are these things and it may get better. But a lot of it was sort of about coping. And it was like this, you know, really kind of looking at maybe a difficult road ahead. And now that's really changing. So there are now two.

FDA approved treatments. One of them is approved in adolescents down to age 12, which is really awesome. And we're going to probably have another FDA approved treatment for adults coming maybe in the next six or eight months if we're lucky. there are clinical trials and there are clinical trials in kids and it's just getting better. So I think though, probably a lot of you have kids.

And that's where it does get a little bit more complicated. But just because there's not something that's FDA approved for what you have or your child has doesn't mean that you can't get treatment. And we'll talk about what off-label means and the different options. But I kind of have some rules, so to speak, when I treat kids. And one is that we need to treat the patient. I am treating the patient. I'm not treating myself. I'm not treating their parents. I'm treating that child in front of me.

And the 18 month old who maybe has really severe hair loss, I want their hair to come back and their parents want their hair to come back. But that 18 month old doesn't have an awareness of it right now. And so that's a time where I'm not going to do something super aggressive because I am treating him or her. I care about how this is changing or not changing the way the child kind of interacts with the world.

We need to treat the patient and not ourselves. And also the treatment should never be worse than the disease. So historically, a lot of the treatments that have been done for

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alopecia areata are uncomfortable. Injections, like injections in your head, they hurt. They hurt in an adult and imagine in a child. And so if it's a treatment that's causing anxiety or discomfort, then maybe that's not the best idea.

When I see a patient, this is sort of like the art of medicine. And I feel lucky because I've gotten to see so many patients over the last many years. And is becoming more intuitive in terms of what am I thinking about based on all these different factors. And these are the things that I go and I talk to other doctors about because it's not simple. It's not like, you have this

You have a broken bone and you put a cast, like it's not straightforward. And there are so many different things that we have to think about. How old is the patient? How severe is their disease? How long has it been since they've had hair? How was it affecting that, right? How motivated are they? How motivated is the family? And then also sort of risk tolerance is really important too. So there are a lot of things that we think about and there really isn't sort of a one size fits all. But for me,

Really the most important thing is how the alopecia areata is affecting the child. So the way I kind of think about it, is it affecting the way this kid interacts with the world or the way that the world interacts with them in any sort of meaningful way? And for me, that's a time to think really about treatment or maybe being more aggressive with treatment. Is the alopecia areata potentially changing the child's trajectory? You know, I see kids who, you know,

used to be a great athlete, they're no longer playing whatever soccer lacrosse because they can't wear a hat or somebody made fun of them or whatever. Is it taking their life on a different path? And then I think honestly, the biggest thing, and this goes along with this trajectory is,

We always talk about risk and benefit. OK, what's the risk of the treatment versus the benefit of the treatment? I think in alopecia areata and actually a lot of things that we do in dermatology, we're kind of really thinking about what would happen if we don't treat? What is the risk or the consequence of not treating? And I've seen just today, I saw a couple of patients who are some of the first kids I ever put on oral JAK inhibitors. And two girls, actually, they in middle school. And this was like,

was kind of pushing the envelope and I was a little nervous, but it was affecting them in a really big way. And fast forward, one of them is a freshman in college. The other one's about to graduate college and kind of thinking about their life over the past seven or eight years. It's really different because we made that decision. And I'm not saying that it's better, but it's different. And it's kind of, think, what it was meant to be without alopecia areata And I think that's, for me, something that's really important. So there are...

Lots of options. Sometimes I say, like, when you have a long list of options, it means that nothing is sort of reliably effective. And it is true that sometimes it really is kind of trial and error. And what's really hard about hair is that everything takes time. So it's really, you know, it's not like you have a rash, you use a cream. OK, two weeks later, you're not better.

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All right, we move on. Hair takes so long to grow. So any treatment we do, we're not going to see the results of for a few months.

So that makes it really difficult. So we can use corticosteroids. So these are things like the injections, topical steroids, things like clobidazole or mometazone or fluocinonide, oral steroids like prednisone, irritants and immunotherapy. These are things like TPCP or squaric acid. There's something called anthraline, which is like an old school psoriasis medicine. It's tar-based and all of these things, the idea of them is just sort of

create actually a little bit of a rash with the idea that with that rash, you bring in kind of a different arm of the immune system and sort of get the part that's causing the problem. JAK inhibitors, we're gonna spend a lot of time on minoxidil, which is one of my favorite medicines. And then we'll also talk about Dupilumab or Dupixent. So we're gonna start with JAK inhibitors, because this is the big thing. Everybody's talking about JAK inhibitors and these medicines have really...

really revolutionized the treatment of not just alopecia areata, but a lot of diseases that we see. So we are treating conditions with these medicines that we really never thought we would have good treatment for. And so the way they work in alopecia areata is that they target the immune pathway that's kind of over active in alopecia areata. So sometimes I'll say to little kids, I think one thing for little kids also to reassure them that they're not sick, they're healthy.

Nothing's wrong with their body. Their body is totally healthy. And sometimes I'll tell them that actually their immune system is like extra strong. Their immune system is like kind of trying to be a superhero and really just needs to be like a regular guy or girl. And so when I was doing this yesterday, putting some slides together, I'm like, I really need to do a better job at sort of showing this. And so this is maybe like corny and awful, but we're going to give it a try. And I was pleased with my PowerPoint.

slides here, my skills are getting much better. But they're still very elementary, by the way. OK, so here we have a hair follicle, right? Our whole body is covered in hair follicles. We've got them everywhere. And what happens in alopecia, normally, the hair follicle is the place where the immune system is not allowed to go. So it has what we call immune privilege, all right? So it's a place where the immune system, it's like, you're not allowed here. But in alopecia areata, in the setting of

sort of genetic predisposition plus these triggers that we don't really understand, that breaks down. And what happens is you get this influx of immune cells, which I'm representing here as soldiers in an army. If you look very closely, these are actually female soldiers, which I thought was really cool because yeah, I like the like laughing emoji.

I'm trying, OK? But hopefully this will help you visualize it, right? Because I'm not a scientist. And when I see the drawings and the diagrams, I'm like, this is too much for me. So what happens is you get this army of immune cells that comes in, OK? And they're like, our job is to get rid of these hairs and keep them from growing, OK? But we all know that armies, they

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can't last forever at the front line, right? What do they do? They have to call for backup, OK? So they're like,

We're getting tired up here, like we need some help, right? And so they pull their handy-dandy cell phone and they make a phone call to more guys, okay? The rest of the army that's waiting, all right? And so the way they do this is a pathway in the immune system called the JAK-STAT pathway, okay? So JAKs are proteins that basically their job is just to transmit messages, all right? And so...

What they do is enable that signal to get back to the people waiting in the wing so that those army folks can come up and replace the ones that are causing the problem. And so you get this perpetual cycle of people at the front line making it so the hair can't grow. And so again, that's done by this sort of communication line in the immune system, this phone, whatever cell signal, you will, called JAK-STAT. And when you

when you inhibit JAKS when you have medicines that grab on to these proteins, it's like they're basically taking a superhero going after this radio or cell signal that's making it so that message can't get to those other army guys so that they don't come back in. And eventually, the guys at the front line, get tired, they give up, they go away. The hair can grow. OK?

And the JAK-STAT pathway spins. OK, so this is sort of a little bit more sophisticated, but still like Britt Craiglow version of what's happening. So for those of you who are more maybe science oriented. So when you have in the hair follicle, have a cell that's sort of around the follicle. And then you have these immune cells. So this blue thing right here is basically like the army guys. OK, so they come in and they start communicating.

cell is also communicating with them. And these are sort of like the army guys on one side. And so this cell is spitting these purple triangles, which is a cytokine called interleukin-15. This is sort of a communication signal. This cell catches it with its receptor here on the surface of the cell. And then you can see there are the JAK proteins waiting inside the cell to take that message. They carry it to the nucleus of the cell.

This influences gene transcription, which makes this cell spit this other cytokine called interferon. And that binds on the other side, and that message gets transmitted the same way. So on two sides of this positive feedback loop, we have JAK proteins at the heart of it. And so what they're doing is taking these messages, they're making it so that army is still at the front lines there. And again, by inhibiting them, we take it so that message doesn't get transmitted or fewer.

of those messages get transmitted, sort of like a dimmer switch. So hopefully that helps, because think sometimes people think that they grow hair. They don't really grow hair. They just allow the body to do what it wants to do, but it's not being allowed to do. So these are the two JAK inhibitors that are approved for the treatment of alopecia areata. When you have a

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like a medical talk, usually we can only use the generic names, but since most of you probably know these as the brand names, I'm going to have both here. And I'll probably just use the brand names because that's what people are more familiar with. So Olumiant is the first one that was approved. That was approved last summer, 2022. That's approved 18 and over. And then we have Litfulo which is approved just this past summer for patients 12 and older. They're both approved for severe alopecia areata. So that's the labeling of these.

see in the clinical trials, all of the patients had to have at least 50 % hair loss. But one thing that's nice about the indication statement is that it doesn't define percent of hair loss. And it's true that a lot of insurance companies want patients to have 50 % hair loss in order to approve them if they're the right age. But nevertheless, they're approved for severe AA. And I think severe is really not just about how much hair is missing.

There's lots of different JAK inhibitors. There are lots of sort of cousin drugs. And you may hear some of these names, especially Xeljanz. This is like the original JAK inhibitor that was approved first for rheumatoid arthritis. It's the one I've actually probably used them. I definitely have used the most of in children because it's been around the longest. But there are these others, Rinvoq those are approved for eczema in adolescents. But none of these is approved for alopecia areata. OK, so if they get used.

for alopecia areata no matter how old the patient is, they're considered off-label. And like I said, we're gonna get to sort of off-label and what that means for you in a little bit. So I'm gonna take you through some of the clinical trial data, really just sort of at a high level so you can have a sense of how people do on these medicines. if you're, and everybody's different, but I find in general...

the alopecia areata of community to be very involved and know so much and be like, yeah, I read that paper. And I'm like, wow. So that's really cool. And I commend all of you for keeping up with the literature and doing your homework and advocating for your kids because it's really important. And I tell people, if you have skin cancer, I really can't help you. I know a lot about this because this is what I do. But a lot of dermatologists, this isn't what they do. And so sometimes it does have to come from a patient or a family to say,

I heard about this or I learned about this. What do you think? Would you be willing to try this for my child? OK. And I think you'll find that some people aren't, but many are. And there's literature and data and things that kind of help support you in that path. So the SALT score, SALT stands for Severity of Alopecia Tool. And it's basically, it's literally just a measure of how much of the scalp is involved with alopecia. OK. It's a little counterintuitive, I think, because the SALT score of 100

means 100 % loss, not like 100 % hair. Because you usually think, be like, 100, you got 100 on your chest. Like, that's great. 100 means 100 % loss. So no hair anywhere. A zero is 0 % loss. So the more hair you have, the lower the number. So remember that when we look at the data. And basically, there's ways to do it. You kind of just look at the scalp and approximate how much is.

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involved. So, Olumiant like I said, it was approved in 2022. There are two approved doses, two milligrams and four milligrams. It's approved only for adults, but there are clinical trials happening in children, and I'm going to show you how to find about those. But I do want to show you the data because I think we have a lot of great data from the Olumiant trials, and really we see in general kids and adolescents do similarly to adults. I would say in

In my experience, think kids tend to actually do even better. But nevertheless, it's nice to have this kind of data. And so basically, you don't have to get well into these graphs. essentially, this is looking at the percent of patients in the trial who achieved a salt score of 20 or less, which means 20 % or less hair loss at the end of.

36 weeks or nine months. OK, so this is a long time, right? Hair takes a really long time to grow. So you can see on the x-axis here, we have weeks and eight weeks, nothing much is happening. 12 weeks, some people are just barely starting to grow hair, but then it kind of continues up. And you can see about, this is going to show you to 52 weeks, but basically about.

At 36 weeks, about 35 % and 33 % of patients on the higher dose. So the red is the four milligrams. And then on the two milligrams, obviously fewer patients get there. But some of them do. And we'll kind of show there are some things that suggest maybe two milligrams would be effective. But I would say in general, in my patients, it depends in kids how much they weigh. But in an adult, sort of for me, no matter how much hair loss they have, I would be using four milligrams.

You just want to get there, right? You don't want to try the thing that might work. And then six months down the road, oh, we didn't achieve it. So now let's go up again. The stakes are really high. So you can see at nine months, about a third of patients are reaching this endpoint. And then by a year, about 40 % of patients are. And so important to note that all of these patients had 50 % or more hair loss. A majority of them actually had complete hair loss. All they could do in this trial was take the medicine, right?

These are all what we call monotherapy trials. You can't have injections. You can't use topicals. You can't take minoxidil. So these are the responses in just taking a Olumiant. And as you can see, these curves are kind of keep going up even by 52 weeks. So some patients, even if they aren't quite there by year, maybe they're going to get there a little longer. But I think this is really important to kind of set expectations because one, not everybody responds.

But two, it takes a long time. And again, that's really hard. Like most people, they just wanted their hair back yesterday, right? And you're like, oh, and you're telling me I have to wait six, nine, 12 months, you know? But I think most patients, like when you start to see a little something that it's like motivating and exciting and, you know, most people, you if you're going to get there, you do. And so these are just some examples of patients in the clinical trial. It really is.

It's kind of magic, honestly. I still, my patients know I still, they're still, they're really excited, you know. I'm really lucky I've gotten to see this happen a lot of different times. And it's like,

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every time it's really cool. It's like, you went from nothing to something and this is all because of science. Like it's really, really, it's really neat. But the, know, I always tell people like, if you forget everything I said, like you'll remember the pictures, you know. And so that is cool. But I always say also like, we show the back of people's heads, but if you could see their faces, like usually,

especially if they grow eyebrows and eyelashes back or just the smile on their face. A lot of times they kind of feel like themselves again, which is really kind of our goal. So, okay, so Litfulo this is the one that actually we can use in kids on label in adolescence. There's one dose of Litfulo. It's a JAK 3 tech inhibitor. So you may some places here it referred to as a kinase inhibitor.

So JAK stands for Janus kinase. I probably should have said that in the beginning. And then the TEC family is like a sort of a different pathway. for me, it's also a JAK inhibitor. It's kind of a cousin. It's working a little bit differently, but similar mechanism. And you'll see in the data, their response rates are pretty similar. So their endpoint of the trial was actually at 24 weeks instead of 36 weeks. So that's a little bit different.

And this graph is really super busy because this was what's called a dose ranging study. So they study lots of different doses, including sometimes a loading dose. So some patients got a high dose for a month and then went down. But there's only one approved dose, and that's the 50 milligrams. And that's the purple that you see here. And you can see actually to 48 weeks, 50 milligrams daily, even though it lags behind a little bit.

in the beginning, patients who got the loading dose, it's essentially the same at the end. So about a quarter and then 43 % of patients meeting that endpoint of 20 % or less hair loss, or you could think about it 80 % or more scalp coverage. And again, these were patients who had at least 50 % hair loss. And so this is the results in adolescent. So there were...

105 adolescents in the clinical trial. I have circled the 50 milligrams because again, that's the approved dose. Numbers are pretty similar here, know, a quarter and a half of patients getting there at 24 weeks and then 48 weeks. Okay. And these are just some photos. And this is actually like a nice example because you can see that this patient, so at the beginning, 100 salt score of 100, absolutely no hair, 100 % loss at week 24 had a salt score of 26.

which wouldn't meet that endpoint because it's not less than 20. But then you can see at the end by 48 weeks, really amazing regrowth had essentially all their hair back. And so ~ at that time, did meet that. yeah, it's really cool. what are some things? What's cool is now we have treatments, but then we're also learning about, what might make someone respond better than another? Again, because we see these rates are like

They're not 100%. They're not really even close to that. Again, I think in real life it's different because we can use other things and combine stuff. And so I think that these numbers probably really do underestimate real world experience. But these are some factors that influence response. For sure, in the case of a Lumia with two doses, this just makes sense. Like higher dose, you do better. Baseline severity. So how much hair loss somebody has at the beginning can impact response. And I'm going to show you that.

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And then there's this concept of a current episode of hair loss, which I also think is important. We'll talk about. And then adding oral minoxidil in my experience and the experience of some other people who do a lot of hair loss, I think that can also really help. And we'll kind of go through these one by one. So this is data from Olumiant. And basically what they did was they looked at patients who had 50 to 94 % hair loss versus

95 to 100 % hair loss. So severe versus very severe. And patients who had severe AA, so 50 to 94, less than 95%, you can see almost half of them met that endpoint of 20 % or less hair loss versus only about 20 % of the patients with 95 to 100 % loss. So the more severe the hair loss, especially once you get to complete hair loss,

probably the lower the likelihood of a response or at least at 36 weeks. So what we see is sometimes patients who have complete hair loss, they just take longer and that kind of makes sense. But if you're somebody who has 75 % hair loss, then your chances are almost 50 % on the four milligram dose that you're gonna get to 20 % loss or better by 36 weeks. Okay, and so this is a concept that I think is important.

and not something that even dermatologists really think about. And this is basically how long has it been since you, your child, whomever has had any meaningful scalp hair. So I see a lot of patients, come in, they've had it since they were two. So did they have patches at two and then it re-grew or did they lose all their hair at two? What actually happened? Because that's important. And so what we really care about is for people with

sort of complete or near complete loss, how long has it been since they've had complete or near complete loss? Not how long it's been since they got their first patch. So you have a 20-year-old who comes in, oh, he's had it since he was 10. You get a little more history. Well, he got the first patches at 10. He re-grew. He had some waxing and waning. And then at 15, he lost everything. And since then, he hasn't had any regrowth. So.

his duration of his current episode is five years, and that's the number that counts because that number actually impacts your chance of responding to treatment. And so this is, again, data from the Allumiant study. And they looked at patients. They broke them down between current episode of less than four years or more than four years. And basically, patients who had had complete or near complete loss or less than four years

responded better than those who had it for more than four years. importantly, this does not mean if you've had complete loss for more than four years, you won't regrow, not at all. It's just that the chance is a little bit less, or at least in this timeframe. I just saw a patient back the other day. He had had no hair, literally not a hair for six years. And he started treatment with lipfulo, actually.

like three and a half months ago and he has a full head of hair and he was a kid I was worried about it like oh don't know you know I'm really hoping we get there and and so and I've seen patients with no hair for 10 years and they still grow it back it's just that this is sort of an argument for treating earlier like this is not like let's wait and see like I had a mom today said that she had been told before like wait till she's 18 this is not something we really

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want to wait on if we have a thought about treating then we should we should probably treat you know but

It's also important to know that in little kids where maybe we're not quite there yet or ready, we do have some time. So it's not like we have to treat today if you just lost all your hair last week. No, we've got time. But when you're getting to that four five year mark, this is the time when you think it's something you might want to do. Now is when we should do it.

So how about kids under 12? And so this is welcome to my life. when Litfulo got approved, 12 and up, I'm like, this is so exciting. I can't wait to have actually a drug that I can say, oh, you're this age and you have this. And so we can get this for you, no problem. But now what I realize is mostly I'm just going to see a lot of patients under 12. So kids under 12.

Just because there's something that's not FDA approved for exactly them doesn't mean that you can't treat them. So there's lots of case reports and case series of using JAK inhibitors in younger kids, mostly Xeljanz, but other medicines also. Xeljanz is approved in the United States for juvenile arthritis in patients ages two and older, which is really nice. So we have data about dosing in kids. There's some systematic safety data.

And I often say that, you know, like if this were arthritis, we wouldn't really think twice about it. We wouldn't have this big old conversation like, well, maybe we should, or I don't know, you know. It would be like, no, we do it, right? And I think for some kids, a lot of kids, alopecia reata can be as debilitating, if not more in some cases, than arthritis, right? And again, that's sort of like, how is the alopecia reata changing the child's interaction with the world? And then Olumiant

is approved in Europe for arthritis down to age two. It should be approved there soon for eczema down to age two. But again, if these are used for alopecia areata under age 12, or any age actually, they're considered off-label. And so off-label, I've said it a bunch of times. I probably should have in the beginning explained what I meant about it. But basically, in order for a drug to be FDA approved for

certain condition, so for alopecia areata in patients 18 and older, it has to be studied in clinical trials. So everybody, I often get asked, well, when is Xeljanz going to get approved for alopecia areata? The answer is never, because Xeljanz has not been studied in randomized double-blind placebo-controlled trials for alopecia areata. So Xeljanz will never be approved, FDA approved for alopecia areata. That doesn't mean you can't use it, but will never be on label.

So these approvals are very specific for a certain population, for a certain disease, age, et cetera. And so for medicine, most of what we do in albizeriota is off-label. When you use clobidazole, it's off-label. But clobidazole is not very expensive. And so insurance companies don't really care all that much about things that don't have a big price tag on them.

But medicines like JAK inhibitors, which are what we call specialty drugs, they have to come from a special pharmacy, insurance companies usually have this sort predetermined criteria

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to approve the medication. So you might have heard from your doctor, we have to do a prior authorization. So prior authorization is, OK, I want to order, for example, Xeljanz for my seven-year-old patient who had severe alopecia areata.

When you go into this prior authorization and you answer the questions, it's like, the first thing is, does the patient have one of these diseases? And it lists all the diseases that Xeljanz is approved for. So juvenile arthritis, rheumatoid arthritis, ulcerative colitis, psoriotic arthritis, ankylosing spondylitis, all these things. But it's like, no, no, no, no, right? Because it's alopecia, it's not approved for alopecia. So usually, if you don't meet the criteria, the insurance company says no, okay?

Now, what's cool in the United States is just because an insurance company says no on the prior authorization doesn't mean you don't have a chance of getting it. So this is where you have to do what's called an appeal. If people have questions about that process, we can talk about that. But basically, it is work and effort to try to get these medicines approved off label. And oftentimes, we're successful, but not always.

Sometimes you can get it approved, but if you can or even if you can, clinical trials are like an amazing way to get treatment, but also contribute. So the only reason that we even have these FDA approved drugs is people were really selfless and participated in clinical trials. These were patients who said, I'm willing to do this. I'm willing to go every month and have my picture taken and my blood drawn and all these things.

answer these questions and because of them, all these other people are getting treatment. Clinical trials are unbelievable and they're an amazing way to participate. What's really great about them is that even though there is this what's called a placebo controlled period, so in the beginning you could get the real drug or you could get sham drug, but basically everything in alopecia areata right now,

goes into what's called an open label extension. So even if you don't get the medicine in the beginning, you get it eventually. And then usually you keep getting it until the medication gets approved, if it gets approved. ~ So I have patients who are in the writ-less-citinib or lip-fulo trials. I have a patient who I think got placebo in the beginning because didn't grow hair, got switched over, started growing hair, was on medicine.

long enough through the clinical trial that her hair is like way longer than mine. Now that it's approved, she's on label. We can get it covered by her insurance, but clinical trials are a really great way to participate. every clinical trial needs to be listed on this website called clinicaltrials.gov. I did some screenshots. It's pretty like user friendly actually. ~ And so basically what you do is you go to the homepage, you type in, know, alopecia or yada. If you're looking for a specific trial, like I want to look up the, you know,

Olumiant or baricitinib trial, you put that in, and then you do a search. And when you get to the search, if you just do that, you get all these results. But then on the left side, you can filter. You can sort them. And so what you want to look for is ones that are actually looking for participants. OK, so either you can see here, not yet recruiting or recruiting. You don't

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want the ones that are completed because you're not eligible. I mean, you can look at them just for interest, but if you're actually looking to find a trial.

~ You want to look at ones that are either recruiting or going to be recruiting too. Then you can filter by age, you can filter by geography, there's lots of things. When you actually get to a study, like this is the study for Illumina or baricitinib in kids, you can go see all the locations, you can click on them, you can get the phone number, all these different things and find a location near you.

is ongoing right now. They're enrolling cohorts that are just 12 and up. But once those are filled, they will hopefully be going down to age six. And this, I'm so excited to do this trial because it's a great way to be able to get medicine and then also push this medicine forward. Because again, ultimately what we want is an on-label option for everybody. And then we don't have to these long-term reasons. How do you get it and all this work?

me poking my eyes , writing insurance letters all the time. This is the goal, but we need to fill these studies, have patients go through, and you can see they take a long time. Hair takes a long time to grow. We have to have extensions, et cetera. So really, I would say if you're thinking about this, look into it. You can go learn about it. And these can be a really kind of a cool experience. think also for a child to sort of feel like they're part of something bigger is really kind of neat also.

Safety. We're not going to talk a ton about this because this is a long discussion. And I do think it really warrants a discussion with your dermatologist. These medicines do have what's called a box warning on them. A lot of the data that informed that box warning comes from a very different population, people with rheumatoid arthritis over 50.

who had at least one cardiovascular risk factor, who were also taking this medicine called methotrexate. That's not to minimize it, but we're not always kind of comparing apples to apples. These things have been seen across trials in dermatology, albeit at very low rates, but it's something that you have to have a conversation about and decide whether or not you're comfortable with that risk.

I would say day to day, these drugs tend to be very well tolerated. So it's pretty uncommon that somebody has some side effect like terrible headache or belly pain or something that prohibits them from continuing on. With Olumiant or baricitinib, we keep an eye on cholesterol because that is something that can go up. Also can theoretically affect blood counts, liver function, that's extremely unusual. With Litfulo or ritlecitinib that one you do need to check blood counts after about four weeks of treatment to just make sure they're normal.

you know, whenever we do this, we do it in the safest way possible, right? We check labs, we see patients, you we monitor for symptoms. And so there are for sure some unknowns in kids especially, but I think again, sort of weighing risk versus the risk or the consequence of not treating is often where my discussion is with parents. So if you take a JAK inhibitor, your child does, what do you expect, right? So this is not like a magic overnight thing, you know? It's not like, I think we feel like...

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You're to take a pill and the next morning your hair is going to all be growing . And it would be really cool if it were like that, but it's just not like that. Right? Because first we have to get that cell signal cut , right? So that message doesn't get through. Then the army kind of has to get tired. Then they have to give up. Then the hair has to restart its cycle. OK? And that takes time. So I tell people I want to see something by about four months. Sometimes people are like,

super responders and like eight weeks in they have hair. It's like so cool and awesome, but other people it's more this kind of slow and steady wins or ways. So I want to see something by four months. If we're lucky by nine, 12 months, we're there or almost there. Some people it's just this slow continued forward progress. For me, as long as somebody is continuing to get better, we keep going.

If we're six or eight months in and there's nothing or almost nothing, it might be time to try something else or add something in. Okay. And I would say everyone responds differently. Like I still, you know, I've done this a lot by now and I can't look at a kid and be like, well you're gonna.

get your eyebrows and eyelashes back first, or you're going to grow in uniformly and you're going to grow and patchy. Like it is all over the map. It's totally unpredictable. Kind of like the disease course of alopecia areata, but usually, you know, most kids that they regrow, they do kind of eventually get there. Um, in general, would say scalp does better than brows and lashes, but I have patients who their brows and lashes do much better and they don't get a ton of scalp hair. But for some people, even getting brows and lashes back is huge. Like that makes a really big difference for some patients or many patients. So, um, you kind of just have to go with the flow.

A lot of people say, including dermatologists, well, what happens when you stop? Well, these have to be taken forever, right? Well, this is a chronic disease, right? So for most patients, they're going to require chronic treatment. In some cases, you know, when kids, maybe you have more mild disease at the outset or shorter duration, or we grow really well, sometimes they do try to taper a little bit. But if we do that, we do it really slowly. Like, you never want to just cut the dose in half or stop.

Right? Because if you go backwards, you're like back in time a long time. And especially for kids who like wearing their hair longer, sometimes it's years before some of my patients are comfortable taking their wig off. And so that's something to think about when we think about timing of treatment, but also thinking about pulling back. OK? Because if you start to lose, that ball is set in motion. It's going to take a while to kind of get over that.

So these are just some examples. I'm talking too long, huh, Lisa?

LISA ANDERSON, PHD: (57:31)
We love hearing you and we can stay on as long as.

BRITT CRAIGLOW, MD: (57:34)

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Okay,

I'm almost done.

LISA ANDERSON, PHD: (57:36)
go off camera, but we're here. ready for questions when.

BRITT CRAIGLOW, MD: (57:39)
Okay. I'll finish the rest quickly. Sorry, my patients and all I talk too much to, but these are just some photos of patients who've been treated with JAK inhibitors. It's really fun. Topicals, would say, know, topicals as a dermatologist, like as a pediatric dermatologist, like the Holy grail, the punch line is they don't really work that well. Sometimes I do think patches, eyebrows, eyelashes, you know, topical is something to consider, but if you have really extensive disease, probably not going to help. Okay.

Shifting gears very quickly, and I promise I will be done within the next three minutes. Monoxidil, I think I mentioned at the beginning, it's one of my favorite medicines. It's Rogaine, known as Rogaine, over-the-counter, topical. But I use a lot of oral Monoxidil. It's a really interesting thing, because we used to sort of think that Monoxidil was basically just like fertilizer for hair. So if hair was there, it would grow faster and thicker and better.

Sometimes actually even just by itself, it can help alopecia areata So I have sometimes kids who were trying to get them a JAK inhibitor approved, they start on oral minoxidil, and then a couple of months in, they're growing eyebrows and eyelashes with just minoxidil. So pretty cool. And then there's definitely, in a lot of cases, a synergy with JAK inhibitors when you use oral minoxidil. So this is a patient who grew nothing after six months of treatment with a JAK inhibitor, added oral minoxidil, and then you can see.

had really great regrowth. These are some patients, we didn't talk about prednisone. I don't use it a ton, but every so often I'll do it like in a pulse fashion. These are all patients who did beautifully with that and actually have all maintained regrowth. Okay, last thing is just briefly is Dupixin or Dupilumab. So this is an injectable or biological medicine that's approved for...

Lots of kind of like allergic diseases. So eczema, it's approved for eczema down to age six months. A lot of kids with alopecia areata also have eczema and sometimes we can kind of capitalize on that. What we love about it is it has a great safety profile. What we don't love about it for kids, it's an injection and that part can be really hard. And what's interesting is when it first came , there were reports both of patients, you know, treated for eczema who developed alopecia areata while on it.

but also patients who had eczema and alopecia areata whose hair grew back on it. So it's a little bit of a complicated story, but in patients, especially kids who have eczema or asthma or food allergies or sort of that kind of background or an elevated what we call IgE, which is immunoglobulin E, which is kind of like a measure of your body's tendency toward allergy, Dupixent may be something.

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that can be useful. And this was just a study that showed that in general, it didn't really work that well for alopecia rita, but the people who had eczema or kind of this tendency towards allergies did very well. And so these are some of my patients who have done well with dupixent. This is a little girl. Actually, I her recently. Her hair's even longer now, but she's been on dupixent plus oral minoxidil for a few years and done amazing. These are all patients who have either

eczema or asthma and have done beautifully with dupexin. So I think that was like a whirlwind. Sorry if I talk too much, but hopefully some of it at least was helpful. I think, you know, kind of take home points is like, this is the hard thing. However you feel is okay. We need to remember we're treating a patient and not ourselves. And as a parent, I know I'm a mom is really hard, but you know,

Just remind yourself of that. And sometimes we kind of have to bear the brunt of things, especially for our kids when they're really little, right? But there are, there is hope. There's so much happening. You know, I always say it's like never a good time to have this disease, but like now is better than ever. And for sure, you know, a year or two, five years from now, it's even better. And so I always tell my family's like, when I meet a new patient, like, look, if, if he or she needs to have hair for whatever, kindergarten, sixth grade, this, like, we can probably do it, you know?

Like she's not going to go the prom without hair if she doesn't want to, right? If we start early. And again, but if you decide not to treat, that's also OK. Like none of this is to say that you have to treat. There are definitely patients I have who choose not to. And they have embraced their alopecia in an incredible way and made a lot of good from it and all these things.

But the point is there are choices and I think it's nice to have a choice. So that's it, I'm done. This is one of my patients, first kids I ever treated with cell chance and we were in the New York Times, which is really cool. So that's it.

LISA ANDERSON, PHD: (1:02:14)
That is awesome. You are awesome. Thank you so much. That, you know, it's it is a lot of information, but I know even for myself, I'm sitting here feeling like I want to write things down. But the good news is we have this recorded so we can all go back and.

BRITT CRAIGLOW, MD: (1:02:26)
There

you go, YouTube, that I didn't even know that I would be on.

LISA ANDERSON, PHD: (1:02:30)
And your wonderful slides because your slides were great and fun. I also really liked how you started with this is largely a treatable disease now, which is just such a wonderful take home from all this.

BRITT CRAIGLOW, MD: (1:02:44)

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Yeah, it's so, I mean, it's so different in a short period of time, which is really cool. It's like fun to have sort of been a part of the evolution.

LISA ANDERSON, PHD: (1:02:53)
Yeah, I've done all the work to get us here. So thank you for that as well. So let's try to get through a few questions. I know we're over time, but if you're okay with staying.

BRITT CRAIGLOW, MD: (1:03:01)
No,

I'm good. I'm good. Yeah, I mean, it's my fault that we're overtime.

LISA ANDERSON, PHD: (1:03:05)
There's more than one question along this line. Is it typical to do multiple treatment options at the same time? For example, an injectable corticosteroid and a JAK inhibitor.

BRITT CRAIGLOW, MD: (1:03:15)
Totally. I feel like the name of the game is like, how many things can we throw? We just want to get there, right? So how many things can we do, especially combining more benign things with something like a JAK inhibitor to get people? So I use a lot of combination therapy. I would say it's actually pretty unusual for me to ever use just one thing. So I think a lot of times it's sorting the right recipe for a patient. I'm terrible in...

the kitchen, but in the clinic, like, OK, let you have eczema, let's do Dupixent but let's also do oral minoxidil and maybe we'll do a topical steroid, or patients on JAK inhibitors, they have stubborn patches, they can tolerate injections, that's totally fine. So yes, being on a JAK inhibitor, for example, doesn't mean you can't get steroid injections or whatever. And again, I think that's why in real life, we see lot better results in general than the clinical trials.

LISA ANDERSON, PHD: (1:04:14)
Great. Someone asked the question about if you're using oral minoxidil as a fertilizer for hair, can you stop the oral minoxidil once the hair growth starts?

BRITT CRAIGLOW, MD: (1:04:26)
Yeah, so it's interesting because again, sometimes when we use it, we don't know if it's playing a role in actually getting rid of the inflammation and helping the hair to regrow, or is it just sort of thickening up the hair that's coming in? So usually I don't like to make any changes for like a while. So my goal is always to get patients to regrow. And then we just kind of leave everything alone for a good eight, 12.

18 months, you know, get through several seasons. Cause some people will get patches. You know, it's actually not, I probably should have said this, but I do think of JAK inhibitors of take as taking people from like severe to mild. So some people will get some patches on and that's actually pretty normal. It's very uncommon to go really far backwards. I've seen it, but super uncommon. So, but yes, for sure. You know, I have some pastry, like with minoxidil you grow hair everywhere, but I would say like an alopecia, we just celebrate hair. It's much easier to take it away than it is to put it back. But some kids don't like, you know,

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I have teenage girls who are like, arms are too hairy and they don't like it. If they've regrown, then maybe we slowly wean back on the minoxidil. Other families, maybe they want to try to decrease the JAK inhibitor. So we keep the minoxidil and we take away a couple of pills a week for six or eight months and then kind of go slowly. So yeah, you don't necessarily have to do it forever.

LISA ANDERSON, PHD: (1:05:44)
Right. And since you're reminding me without looking at the questions, I'm going to paraphrase, but there are a couple of questions here about being on a JAK inhibitor, having regrowth and then getting those patches. How are those treated? Yeah.

BRITT CRAIGLOW, MD: (1:05:57)
So that,

mean, I say that's really hard when it happens. It's like, I mean, I always say hair loss is traumatic. And I think like, when you're doing well, and then you get a patch, it's like, it can be like PTSD. It can be really hard thing. Like, oh my gosh, here we go again. Right. Um, but I would say in general, like I said, it's uncommon to have it be super severe. Okay. So a patch like when it first, when I was first treating patients and they got patchy, Oh my gosh, like, Oh geez. Like, but now I'm like, okay, this is pretty normal. Not like it's.

fun when it happens, but usually it's like manageable. we'll, you know, I saw someone today who this happened. So maybe we'll do, you know, if they're a little bit older and they can tolerate injections, maybe we'll do injections. That definitely can help. I think a lot of people will say, well, I did those before and they never helped. Well, you weren't on a JAK inhibitor before, right? So the idea is that the JAK inhibitor is kind of like decreasing the level of inflammation. So we have a little bit, we don't need to do as much to kind of get over the hump and that patch is like we did before, right? So,

topical steroids, injections, nothing, know, waiting it . Sometimes if it's more severe, depending on what drug you're on, like Xeljanz sometimes we can increase the dose. If you're on two milligrams of Olumiant you could go up to four milligrams. So there are some things to do to deal with that. But I would say, you know, I get that it's like awful when it happens, but it's usually pretty mild.

LISA ANDERSON, PHD: (1:07:19)
Great, thanks. What's your viewpoint on sourcing JAK inhibitors from overseas? So tofacitinib for example.

BRITT CRAIGLOW, MD: (1:07:26)
Yeah, so

I personally am not comfortable with like generic Xeljanz manufactured. I know there are people who get it from India or Bangladesh. And I think while it may be fine, the sort of regulatory oversight is not what it is here. If you're getting, you

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branded medicine that's actually made in, like if you're getting Xeljanz made by Pfizer from India, that's kind of a different story for me. But I think my concern isn't so much that it's not tofacitinib because it probably is, but like what else might be in there? And there are stories of contaminated drugs all the time. And I think that, especially in a child is really scary. It's like what we don't totally know what we're doing. And so while I understand

and it's like really hard to get these medicines. And as a parent, I get it. do worry about that a little bit. Canada has approved generic tofacitinib and it's like regulated in a way sort of like the FDA. That is something that I am more comfortable with.

LISA ANDERSON, PHD: (1:08:44)
And related in terms of cost of medications, how are you finding insurance reimbursement these days and the appeals or is that is that getting a little better since we.

BRITT CRAIGLOW, MD: (1:08:55)
Yeah,

I mean, do think it's getting better. It's really hit or miss know, it's like, you know, people ask me, what's the best insurance to have? And I'm telling you, like, I think two people could have literally the exact same insurance and get two totally different answers. You know, it's very frustrating. I would say I've like lost years of my life because of these insurance companies and the pharmacy benefit managers. you know, often I think

it feels like sometimes their whole goal is just to get you to give up. And that's, again, where buckling down is, I think, can sometimes be in your best interest. One thing that we've started doing with appeals is having patients and families write letters also. I just used to write a letter and say, this is why he or she needs it and the things that they've tried and this is all the data and the literature.

you know, oftentimes that would work. But I think the goal is to kind of help the person on the under sort of on the other side, you know, the recipient of the letter get that this is like a human being that we're talking about. This isn't just like a number. This is someone's kid and this could be their kid. And I, you know, some of the letters that my patients and parents have written have been like, just really incredible. And I'm like sobbing, you know, at my desk, but

just to say what this is like and what it's meant for you and your family. And if it feels kind of like you're pleading, that's OK. You just want to get it. And so usually there are multiple levels of appeal. If you exhaust the internal appeal process with your insurance company, there should be an option for what's called an external appeal. It's more work. But this is where somebody outside the insurance company, usually it's someone decided by the state.

~ looks at it and sometimes it's actually multiple dermatologists and you sort of put together this whole, you know, packet for them. And I have many families who've had to go to an external appeal, but actually gotten it on that. So don't give up if you exhaust the, you exhaust it within your own insurance company because that external appeal, think again,

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and this is where you, you write a letter to the child. If they're little, they draw a picture, you send photos, you have the

teacher write a letter, if there's a pediatrician, if there's a psychologist, if they're a sibling, idea is you sort of like, want to kind of just like make a case for it, right? And yes, it's an effort, but like if you get a yes, then it's like totally worth it.

LISA ANDERSON, PHD: (1:11:16)
Okay, great, great advice. Okay, switching gears a little bit. What are your thoughts on giving young children Allegra to help with alopecia areata?

BRITT CRAIGLOW, MD: (1:11:23)
yeah, I always say the Facebook groups love Allegra. Look, I am.

LISA ANDERSON, PHD: (1:11:27)
you can just tell everybody just in case they don't.

BRITT CRAIGLOW, MD: (1:11:29)
So

Allegra is fexophenadine It's an oral antihistamine. It's like what you take for seasonal allergies. I would say the data for Allegra is pretty minimal. There's a little data to support its use. think that I don't really have any issue with it. think if a kid, for sure if a kid does have symptoms of seasonal allergies, like that makes sense, right? Maybe, and we do see this sort of seasonal variation sometime and maybe.

And some kids that little bit of inflammation related to the allergies is kind of tipping the scale. I, you know, I do have patients who, lot of patients come to me on it. Sometimes I will add it like if I'm not getting there to see. yeah, I think it's, I think it's fine.

LISA ANDERSON, PHD: (1:12:14)
And there was another question about, do you recommend biotin or we can maybe say other nutritional supplements?

BRITT CRAIGLOW, MD: (1:12:19)
Yeah,

so I don't. think, so biotin is just sort of like a master marketing thing. I don't know how this happened, but there's actually almost no data for biotin and hair. It's really interesting because it's in all the hair gummies and everything like this. biotin can actually, the reason I actually don't recommend biotin is it actually can interfere with certain laboratory assays. And so for example, thyroid.

like thyroid function tests, can get like inaccurate results if you're taking biotin and the same is true for like cardiac enzyme. So this is especially important in older patients because you can like, so if someone has chest pain and you think they might be having a heart attack, if they are taking biotin that can actually impact that number and, you know, give you a false

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read. I, know, if you want to take a multi, your child take a multivitamin, I think that's totally fine, but I don't.

I don't think you need to go wild and crazy with supplements. And the other thing about supplements is they are still not really regulated. They're highly unregulated. And so, you know, sometimes we think we're giving one thing and, know, we're actually not. So I think if they're eating, you know, I mean, my kids' diet, I wouldn't really say it.

Well around him, but you know if they're eating you know mac and cheese and chicken nuggets all the time give them multivitamin if they get broccoli Sometimes like you probably don't have to

LISA ANDERSON, PHD: (1:13:46)
I like that. ~

BRITT CRAIGLOW, MD: (1:13:49)
I

joke that my kids think that like different shaped pasta is like different food groups. So no judgment ever on the nutrition.

LISA ANDERSON, PHD: (1:13:58)
Okay, another question. Is topical minoxidil as effective as oral minoxidil when combined with JAK inhibitors?

BRITT CRAIGLOW, MD: (1:14:03)
Yeah, I don't think so. But if there's like a contraindication to oral, then sometimes I will or someone doesn't want to do oral, sometimes I will do. But I would say in general oral works better. And it's just easier. Topicals are hard. And that's the other thing about using topicals. It's like, just do it. It's a lie. When you got a squirmy kid or they don't want to do it, it's also putting attention on the hair. I think kind of recognizing that that

doing that night after night also can be difficult. It's important to think about also in terms of treatment.

LISA ANDERSON, PHD: (1:14:40)
With the use of JAKs and oral minoxidil, does this mean that methotrexate is no longer a recommended treatment?

BRITT CRAIGLOW, MD: (1:14:47)
So I mean, yeah, kids under 12. I mean, I would say the data suggests that methotrexate doesn't work very well. Are there some cases in which it does work? Maybe. The majority of data supporting the use of methotrexate also is people who are taking it combination with prednisone, which is really not safe long term. I think if you.

LISA ANDERSON, PHD: (1:14:49)
I will.

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BRITT CRAIGLOW, MD: (1:15:14)
If you can't get a JAK inhibitor, you can't get in a clinical trial, then it is something to try, but I think it's a lot less likely to be, you know, effective. But some people may, you know, regrow with it.

LISA ANDERSON, PHD: (1:15:27)
Okay. A couple of questions here related to clinical trials and thank you for bringing that up. Maybe I can just say that we have some information about clinical trials that are enrolling on naf.org backslash studies. And when we share the recording of this webinar, which we'll do tomorrow, we can include some information about some currently enrolling clinical trials for under 18. Let's see.

JAK inhibitors and football, high-intensity sports. Any concerns there?

BRITT CRAIGLOW, MD: (1:15:57)
Not for me. No. mean, I think a lot of people think about these, ~ they're immunosuppressive. And I think I have sometimes families think that like, their kid doesn't wear a mask everywhere or they can't do sort of regular stuff. this isn't, it doesn't change. It really shouldn't change your day to day. know, some people maybe feel like maybe they get a little more cold, but honestly, that's even not a common thing that I see, you know? So it's not.

immune suppressive the way chemotherapy is or something like that. This really doesn't, it doesn't, it shouldn't change your daily life really at all. Although I will say if kids get sick, you know, if kids are like, if they just get the like the sniffles or they have a cold or something, then, you know, I often say you can keep taking it. But if a child is like really sick, like they have a fever, they're home from school, they're feeling really crummy, then I will often have,

families hold it for a few days. Because the idea is that potentially it could interfere or sort of make it harder for them to get over a viral illness or something. And that's, think, largely theoretical. But it's also, it's OK to miss a few days of it. This is not a thing like if you miss a week, all your progress is going to be lost. You have to be off for several weeks, I think, in general, before you might see some backwards. But again, it's not going to be immediate. So sometimes people come in and they say like,

I taking it and look, still, everything is great. And I'm always like, ooh, when did you stop? three weeks ago. And it's like, boy, we've got to get right back on it because it's going to be months before you see. If you look at these trials, some of them, have withdrawal studies. So you stop the medicine, you see what happens. And it's usually at least eight weeks before people start to lose hair on average.

LISA ANDERSON, PHD: (1:17:39)
We'll wrap this up soon. A couple more questions. Would you suggest a birth control pill for teen girls on Llitfulo to help with hormone balance? Heard that is happening at some research term offices.

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BRITT CRAIGLOW, MD: (1:17:51)
That's an interesting question. I think that's like a very individual thing. mean, you sometimes we use oral contraceptive pill for, you know, girls who get a very heavy menstrual period or bad cramps, or it's really irregular, or they have acne, you know, lots of reasons that aren't contraception. So I think I'd have to sort of know a little bit more of the story there. For sure, these are drugs that you shouldn't.

get pregnant on. if that's a possibility, then having some reliable form of birth control is obviously really important.

LISA ANDERSON, PHD: (1:18:28)
You mentioned not treating young kids, treating the patient, not the parent, et cetera, but does not treating at an early age make it harder to grow hair again later? mean, you talked about this a little bit. My daughter is two. She doesn't notice her hair loss, as you say, but we don't want to make treatment harder in future by not treating now. Right.

BRITT CRAIGLOW, MD: (1:18:46)
Yeah. And so I think I probably shouldn't have said don't treat. It's not that I wouldn't do anything in a two-year-old. It's just that I probably wouldn't put them on a JAK inhibitor. So I do actually usually like to do something because again, sort of what we understand about the science, like if we could kind of maybe get rid of at least some of the immune cells, then we sort of, we might be able to interrupt that, you know, that feedback loop. So I will in kid, like two-year-olds, I might.

You know, I have two year olds who are on Dupixent because they also have eczema and actually someone that have regrown like amazingly. I might use topical, know, topical. So it's not like I won't do anything, but, but again, like I think our window of opportunity, it's like pretty big. And so, but you know, if you lost all your hair at one by the time four years old comes around, that might be a time when I say like, you know, we might want to start thinking about it.

if we want him or her to have a chance at hair. And I think I've learned a lot. Again, every child is really different and every experience is really different. But I think I used to think more, OK, well, it's not really till mid-elementary school that this becomes a really big thing for kids. kids' self-esteem is really congealing around age four, five years old.

And kindergarten's a really big thing a lot of times. And I think, you know, sometimes I have families who, it's very clear that it's affecting their child, but other families, maybe we decide to do it. And it's not until they regrow hair that they're like, wow. Like this was like, feel like I have a totally different kid now. A difference is kids who don't have a memory of hair. I think that oftentimes that's a harder situation because for those kids, it's

it is sort of their identity, like that's who they are and it's not like this big change. So sometimes that's like a harder situation again, because we don't wanna tell them that they're not okay the way they are because they are like they're all perfect however they are, right? But if you decide...

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I've seen this in some kids like 10, 12 years old who maybe they've had no hair since they were four or five and they're like totally cool with it. Some of them actually really do, believe, like it. They're fond of it. That's who they are. But the question is, is that always going to be the case? We don't know. if when they're 20, are they going to wish we had done something when they were 10 or 12? And that is really

hard situation again, because we don't want to imply that they're not okay like they are because of course they are, And sort of a 10 year olds level of understanding and sophistication and thought really isn't quite there to sort of think about their future self in that way, right? So some of the hardest actually treatment kind of decisions have actually been in those kids where it's like everything is okay right now.

you know, and, but are we gonna regret like that we didn't do this, you know, in five years when he or she wants to try it and then it doesn't work, you know? So this is hard. I mean, it's all, there are no right answers. And I think, like I said to a family today, like, I think a lot of it's kind of a gut thing, you know, like we can look at the data and we can talk about all these things, but really it's like what.

what feels like it makes the most sense to you and your kid.

LISA ANDERSON, PHD: (1:22:26)
I think that feels like a good place to wrap up and say thank you for sharing your tremendous knowledge, wisdom, all the experience that you bring to this. We really appreciate you and ~ we're grateful that you could share all this with the community. And as you mentioned, we will continue to share it .

BRITT CRAIGLOW, MD: (1:22:47)
Oh God. never watch it. I can't ever watch any of these things because I'm like, it's so cringy. know, that's the way I look, that's the way I sound. But I really appreciate the people coming in and, you know, hopefully you leave feeling like, oh, you know, they're.

like there's hope and this is like an incredible community. And I think like, if you don't have, you know, a mom friend or a dad friend or your child has never met anyone with alopecia areata, like that's really special. And so even sometimes just asking like your kids' dermatologist, you know, you could look through NAAF, but even like I've connected, like, you know, I have multiple patients. So I'm like, wait a second. I have a patient who also lives in, you know, XYZ state and they're around your age. Like, would you like to add?

Like recently, parents sent me a photo of these two little girls who are like the same age and come, you know, and they met and that shared experience is like, it's just like really special. So I would encourage you and NAAF is like a great way, you know, to have a

LISA ANDERSON, PHD: (1:23:52)
Yeah,

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not for just shameless promotion, but the NAAF conference, which this year will take place in Washington, DC on June 27th to the 30th, I believe, is a great place where families connect and there's lots of kids and there's a kids camp. So that's definitely a place where sometimes people are meeting other people with alopecia areata for the first time.

NAAF support groups, which I'll share a slide about that also as another way to connect with folks. All right, well, thank you, Dr. Craiglow. I am going to share my screen and just wrap this up.

BRITT CRAIGLOW, MD: (1:24:21)
So much

LISA ANDERSON, PHD: (1:24:29)
Okay, so thanks everybody in the audience for being here today. Please share your feedback on this webinar and also help us plan future presentations. You'll get a link to a short survey when you close of this webinar and you can answer the questions there and your feedback is really greatly appreciated.

I want to share this resource from NAAF with you. This is relatively new, our Dr. Finder. How to find a doctor is a question that frequently comes up on these webinars. So we've created a tool to help. You can check it on NAAF's website. The Dr. Finder lists board certified dermatologists based in the US with experience in treating alopecia areata, and the listings are searchable by state.

This list is still in its early stages, but we expect it to continue to grow. We add names, new names to the Dr. Finder each month as we get permission from the doctors to be included. So we invite you to check it . And NAAF is grateful to our partners, Eli Lilly and Sun Pharma for supporting this project.

Just to touch on again, connecting with other people with alopecia areata, something else new from NAAF are virtual support groups just for teens ages 12 to 17. This is pretty new. These are virtual support groups where teens can have a place to talk with other teens about living with alopecia. So we have a group that is just for teen girls that launched recently and one for boys that is just getting underway.

Each group has two volunteer co-leaders who are either support group leaders from NAAF or have youth mentor experience. And these groups are open to US-based teens. For more information on these groups, you can ~ email us at support at NAAF.org.

And then switching gears, our next webinar will be on dating with alopecia. This webinar is taking place in February, February 13th at 7 p.m. Eastern, 4 p.m. Pacific. Dating can be challenging for anyone, but after an alopecia areata diagnosis, it's often scary and overwhelming. In this webinar, we are having two licensed psychotherapists, Alison Mann and Donna Astor-Lazarus, who will discuss how to overcome obstacles such as anxiety,

a negative body image, how to discuss alopecia and when to tell a date you wear wigs and more. Registration for this webinar is now open at NAAF.org. And don't forget that NAAF

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has a number of resources and programs for the alopecia areata community, support groups, our youth mentor program, the doctor finder that we just mentioned, conference not listed here, news and webinar links and information on how to get involved.

To learn more about NAAF and the resources we offer, please visit NAAF.org or email us at support at NAAF.org. And this concludes today's webinar program. Thanks again, Dr. Craiglow for being here, for staying on extra time to answer questions. And thanks everybody in the audience for being here. We look forward to seeing you all at the next webinar. Okay, take care, everyone.

BRITT CRAIGLOW, MD: (1:27:29)
Everybody, thank you.

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