Webinar Transcript: Understanding Insurance and Patient Assistance Programs for Alopecia Areata Treatment

Dr. Jennifer Fu, Maecy Torres, & Janelle Ball

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[00:00:00]
Lisa Anderson:
Welcome to the National Alopecia Areata Foundation's webinar, Understanding Insurance and Patient Assistance Programs for Alopecia Areata Treatment. Joining us today is Dr. Jennifer Fu, Maecy Torres, and Janelle Ball. 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 have disabled chat for this webinar session. Please post your questions for our speakers in the Q and 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 the recording via email. And finally, please share your feedback with us. At the conclusion of the webinar, a link to a short survey will pop up in your browser window. Please complete the survey there. We love to hear your feedback and we use your input to plan for future webinars.

This webinar is part of NAAF's You Are Not Alone Education and Empowerment webinar series. NAAF gratefully acknowledges the support provided for this webinar series by our partners Lilly, Pfizer, and Sun Pharma. Before we get started, I'd 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 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 a choice to embrace or live free of alopecia areata. To learn more about NAAF's support resources and research and advocacy activities, or to join us as an advocate or a supporter, please visit our website at naaf dot org.

And now on to today's webinar, Understanding Insurance and Patient Assistance Programs for Alopecia Areata Treatment. We're excited to have doctor Jennifer Fu, Macy Torres, and Janelle Ball here today to share their expertise. Let me tell you a little bit about them. Doctor Fu is a dermatologist with expertise in hair loss disorders and is a fellowship trained Mohs surgeon. She sees hair loss patients in her private practice and at UCSF where she directs the hair disorders clinic and oversees clinical research. Doctor. Fu works closely with patient advocacy groups such as NAAF and is particularly interested in the intersection of social media use, healthcare utilization, and mental health in adolescent patients with alopecia areata. Maecy Torres is a certified pharmacy technician with over five years of experience as a medication access specialist at UCSF Specialty Pharmacy. She supports multiple clinics, including dermatology, by helping patients access their prescribed biologic therapies. In her role, she guides patients through the complexities of insurance navigation, prior authorizations, co-pay assistance, and manufacturer support programs. And Janelle Ball is the CEO and founder of BC Educators, a health care company focused on improving access to specialty medications. She is a biologic coordinator turned consultant speaker and key opinion leader with over fifteen years in the medical field. Janelle co-created a national training program for biologic coordinators, developed an access focused app, and hosts the That's Derm Good podcast, blending education and advocacy in dermatology. Thank you all so much for being here today. I know we have a lot to talk about, so I'm going to go to the next slide and turn it over to you, Doctor Fu.

[00:04:14]
Jennifer Fu, MD:
Thank you so much. So, thank you to Lisa. Thank you to NAAF. We are so pleased to be with you today to discuss such an important topic that impacts all of our patients. So, let's jump right in. Here's our disclosure slide, as Lisa said. Next slide. I'm gonna start by framing our discussion today so you know what to expect.

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Although there are, of course, many treatments for alopecia areata and the principles that we discuss here will likely be relevant for getting coverage for other therapies, the focus of this particular webinar will be on obtaining insurance coverage specifically for the FDA approved oral JAK inhibitors for the treatment of severe alopecia areata. So the three of us wanna show you how the process is supposed to work and also how to overcome common obstacles. So you've made this decision with your health care provider. You're excited to start on treatment. What comes next? Who's on your team? Because that's gonna be critically important. And what can you, the patient, or perhaps the parent of a patient, do to help facilitate the process? Next slide.

So, it really takes a whole bunch of very dedicated team members. Maecy and Janelle and I are gonna take turns teaching you how to effectively work with your health care provider and their staff, your specialty pharmacy, and the pharmaceutical company that makes your medication. My job is gonna be to start out by reviewing some alopecia areata terminology, and in particular, how you and your health care provider are gonna determine the severity of your current episode. Because right now, the oral JAK inhibitors really are approved for severe alopecia areata. So we're gonna talk about what that means. That'll be an important data point as you begin this process. Maecy is then gonna take over and talk to you about prior authorizations and specialty pharmacies and how you can work with your health care team to streamline the journey through appeals and denials if they occur. And, unfortunately, they're still common. I'll circle back in to talk about the external review process, so how you can move outside of your insurance provider's realm in case, you end up with a denial, what next step you can take. And then finally, Janelle is gonna teach you how to maximize your use of patient support programs because there are a lot of those. So we know that we're gonna be throwing around a lot of terms, and we're gonna try to define those as we go, but as a resource, we'll also be posting a link in the chat to NAAF's web page on the topic, which has a really helpful glossary of terms that you can reference. Next slide.

Alright. Let's start with just alopecia one zero one. So first, although you often hear people, including your health care provider, sorting alopecia areata to just alopecia, It's important to know that the accurate and full diagnostic name for this common autoimmune form of hair loss is alopecia areata, and it's especially important to use that very clear terminology as you go through the insurance process. So, alopecia areata, very common, affects, nearly seven million people in the US and two percent worldwide. Next slide. Commonly affects the scalp. It can also lead to hair loss on the face and other body sites. It affects all ages, all genders, ethnic groups. First diagnosis does tend to happen at a young age, so we do see a lot of young people, but you could also be diagnosed at a later age. You may still hear us, your health care providers, describing alopecia areata episodes using older terminology. So, patchy loss is when a patient has isolated patches of hair loss. Totalis is when somebody has complete scalp hair loss or universalis when every hair on the scalp face and the body are gone. But you're also gonna notice nowadays in clinic, that when it comes to documenting scalp severity, your insurer is going to want your healthcare provider to have calculated and reported your current percentage of scalp hair loss. So, that's actually going to be a number, and you may hear this percentage of loss referred to as a SALT score. SALT stands for severity of alopecia loss tool. So, a SALT twenty five, for example, is gonna be twenty five percent scale pair loss, SALT fifty is fifty percent scale pair loss, and a SALT a hundred is a hundred percent or complete scale pair loss, what we might in old terminology call totalis. Eyebrow and eyelash loss, nail involvement, these are all common, and these are sort of special sites that can really have functional consequences. We'll talk a little bit later about how you really wanna document that, have it be in your chart with your healthcare provider. If you are writing your own letter to your insurer, you also are gonna wanna document how these special sites might be affected and how, that affects you functionally. Next slide.

So, we all know in this community how deeply alopecia areata affects those of us with this condition. Sixty nine percent of adults with Alopecia areata report feeling anxious in social situations. Fifty four percent report interacting with their friends less often than they want to, forty five percent report missed time at work, and seventy five percent report that alopecia areata impacts their self esteem. You know, this is not news to anybody who's on this webinar. Next slide.

What's important and what you'll see here is that these psychosocial impacts along with other factors are now being incorporated as they should be into the way hair experts categorize disease severity. So, again, remember, oral JAKS currently approved for severe alopecia areata. So, we have to work on the definition of severity when we're talking to our insurance providers. So disease severity and categorizing that really directly impacts our ability to con to convince insurers to cover treatment costs. So looking at this alopecia areata scale, which many hair experts now rely on, it's widely accepted that fifty to a hundred percent scalp hair loss represents severe disease. But many hair experts feel, and will argue with your insurer that twenty one to forty nine percent scalp hair loss may also be categorized as severe disease, especially when there is an additional exacerbating factor, such as negative impact on psychosocial functioning, noticeable eyebrow or eyelash involvement, failure to

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respond to past treatments. So that's important to document, or diffusely rapid loss. So patients in this category may also be good candidates for oral JAK therapy. Next slide. So, there are now three oral JAK inhibitors officially FDA approved for the treatment of severe alopecia areata, that's two for adults, and I'm gonna use the brand names, Olumiant and LEQSELVI, and one for adults and teens twelve years of age and older, that's Litfulo. So just wanted to, make a note that NAAF has other wonderful webinars that go into the nuances of these treatments. So who's a good candidate, how to prescribe, how to monitor. That's beyond the scope of this webinar, but I do encourage you to delve into NAAF's webinar archives for that information. Next slide.

So in 2024, hair loss experts and NAAF and, some pharmaceutical partners, identified three critical issues that continue to impair our ability to provide good care for you. And of course, today's webinar is focused on the one in the middle here, which is how to address the reality that many of our patients continue to face. Despite the fact that we have these wonderful brand new treatments, they continue to face unequal and, inadequate access to that treatment. So what do we do about it? This is gonna be a great time to transition to Maecy, who's going to tell you next what happens. So what happens after your health care provider has made that decision with you to start treatment, your health care provider writes that prescription, what happens with it? What's the process? And she's gonna introduce you to some of the ways in which if you encounter obstacles, your team is gonna fight for you to get the medication you need.

[00:12:48]
Maecy Torres:
Thank you, Doctor Fu. Again, thanks everyone for coming. My name is Maecy Torres, and I am one of the medication access specialist at UCSF, It's a specialty pharmacy. Again, what I do is we support UCSF patients by navigating the complex processes of insurance benefits, prior authorizations, financial assistance programs, and ensuring patients can get access to their medications. Next slide, please.

So today we're going to talk about what prior authorization is, how the process works, the requirements to submitting a PA and what that results mean, and the difference between a specialty pharmacy versus your local pharmacy. Next slide, please.

So what's a prior authorization? So some medications need insurance approval before they're covered, and that's called a prior authorization or also known as a PA. So it's basically your insurance double checking that the treatment is a right fit for you. If a prior authorization is not done, coverage can be delayed or denied. Normally, a doctor's office sends the prior authorization request to your insurance company, but sometimes a health care team or a specialty pharmacy acts with access to your medical records can help with this process. Next slide, please.

So the first step is your doctor sends the prescription to your pharmacy. Next, the pharmacy checks if your insurance approval is needed. When you're prescribed a medication that requires a prior authorization, your doctor or health care team initiates that process. They'll submit a form of request to your insurance provider and supporting clinical documentation along with it. That's basically medical information that helps your insurance company understand why the medication is being prescribed. The insurance then reviews it and clearly, and the clearer the information, the higher the chance of it getting approved. And finally, your insurance decides whether to approve it, deny it, or ask for more information. And also, please be aware that this process can take days to weeks, so make sure that you're actively communicating with your doctor to check the status of the prior authorization. Next slide, please. Next slide, Lisa.

Thank you. So when it comes to prior authorization, insurance needs the right information to approve your medication. They'll want to know your condition, how severe it is, and why this specific treatment is best for you. They also look at what you've already tried in the past, like pills, creams, injections, or light therapy, and why those didn't work. For hair loss, your doctor may use salt scores from what Doctor Fu mentioned earlier to measure the severity of the disease. Insurance may also ask for lab results since medications that Doctor Fu went over earlier can affect the immune system and increases the risk of serious infections, including tuberculosis. That's why it's important to do the required labs prior to starting the medication. And all of this helps your doctor's office pull the case for your approval. Again, the clearer the details, the smoother the process and the less less chance of delays or denials. Next slide, please. Okay. So what happens if the prior authorization is approved? When the prior auth is approved, you can then fill it at a specialty pharmacy and pay your usual co pay or coinsurance. Also, please be advised that because JAK inhibitors are specialty medications, you may have a higher co-pay than usual. Janelle will go over this process with you later. And if the PA is also approved for ongoing use, you won't need to repeat the process every time, just only when the approval ends. So, it

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depends on the insurance if they will approve it to the, end of calendar year or for a year. And, also, to for delays getting your prescription, it's best to set reminders, use autofills, or sign up for pharmacy alerts so you don't miss it. Also, at your follow-up visits, be sure to talk with your dermatologist about how the medication is going, any concerns you have, and whether you need refills for your medication. Next slide, please.

So why do you need to use a specialty pharmacy? I know some patients prefer to use their local pharmacy for pickup convenience, but specialty medications are different for your regular prescriptions. Most of the time, you'll need to contact the specialty pharmacy for each refill. They'll check-in with you to be sure the medication is working, watch for side effects, and keep your information up to date. Also, specialty pharmacies are built to handle the extra monitoring the medications require, and they often connect patients with copay cards or assistance programs to help with the cost. Unlike regular pharmacies, they're trained to give you the added support needed for safe treatment. Next step, please. Or next slide.

So what happens if the prior authorization is denied? If your prior authorization is denied, you'll get a letter from your insurance explaining why your dermatologist I'm sorry, explaining why it was denied. And then your dermatologist or health care team can file the appeal and will normally provide more clinical information to support the appeal. You can also file an appeal yourself by contacting member services of your insurance plan. But if you plan to do so, it's usually best to work with your dermatologist since they can provide the records to your insurance needs. If your dermatologist agrees with the denial, they may switch you to a different medication that's covered. And there's also free drug programs available from the drug manufacturers that can help you get the medication either at a discounted rate or for free. Next slide, please.

So there are several reasons why insurance plan denies the PA, but the most common, denials are listed on this slide. First, it could be because treatment for alopecia areata is considered as a causemetic use or not medically necessary, or the prescribed medication is not covered or payable by the plan. Many insurance plans also require patients to try other usually less expensive treatments before they'll cover the specialty medication. Other reasons for denial include small mistakes or missing information in the paperwork or if your medical records don't fully show that you have superior alopecia areata or need this medication. Insurance plan may also deny it as what we call off label use, and we normally see this denial, for pediatric patients that are being prescribed in TRK inhibitors meeting, patients less than twelve years of age. So if both the prior authorization and first level appeal were denied, your dermatologist will determine if filing for external appeal is needed. And, Doctor Fu had prepared a few slides to go over that process with you.

[00:20:39]
Jennifer Fu, MD:
Thanks so much, Maecy. Okay. So what happens? You've worked with Maecy. You've been very diligent. You've been very patient. You've appealed and appealed, but you're still denied by your insurance provider. So insurance providers usually offer several levels of appeal, but what happens if you've exhausted every single one of those? So there is such a thing as an external review, and that's where you're able to plead your case to a higher authority and ask them to overturn your insurance provider's denial of coverage. Next slide. So, each state is different, but generally speaking, you have the right to an external review either by your own state or if your state wants to delegate it, it can go to a federally sanctioned entity. You can use this QR code on this slide, to go to healthcare dot gov for more information. So, just as with internal reviews, which are those conducted by your insurer, your health care provider needs to provide a letter of appeal. And this is gonna include a lot of the information that might have gone into prior appeals. If there's any new data points, they should submit that. If they haven't already submitted photos, they should do that. If you haven't submitted your own letter of appeal, you should do that. So you should be very specific about how alopecia areata has affected your life. Talk about school, talk about work, talk about extracurricular activities, hobbies, how alopecia areata may be affecting your career choices, if that's where you are in your life. Be specific about how it affects you both mentally, but also functionally and physically. So, look up the external review process, available to you based on your state of residence, and make your case. Next slide.

So, I'm just giving you a snapshot of what it looks like in California. So, in California, you can do an external review and they call that an independent medical review, And you can look up past decisions on oral JAK inhibitors for the treatment of severe alopecia areata, so in cases similar to yours, and you can get a whole list of these largely favorable decisions, that have already set a precedent to argue your case in your own external review. Keep in mind that if you win your external review, so in California, if California says, Yeah, we feel like you need to cover this medication, your insurer is then required to approve coverage of your medication,

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even if they denied you in the past. So, that's a fantastic outcome and in my own practice, which is in California, we've done this quite successfully for many of my patients.

K. I'm gonna transition now to Janelle, who's gonna tell you about navigating patient access programs.

[00:23:34]
Janelle Ball:
Thank you, Doctor Fu, and thank you, Maecy. Hi, everybody. So we're gonna talk a little bit about access. I know that is something that is a hot topic, especially when you're prescribed a medication. That's always the first question that I even think of is, what is it gonna cost, and what is available support wise? So, let's go to the next slide. We're gonna have a little guide here that kind of shows you a little bit about what patient support programs are and, you know, how you can get access to them. So these programs are created by the manufacturers. Most, pretty much all the specialty medications that are available right now have, access programs that are available that can kinda help you navigate getting access and getting your medication. So there's different types of access depending on what kind of insurance you have. So if you have, a commercial insurance, you know, you might have the ability to get enrolled into a bridge program. Or, if you have a Medicare or government funded program, then you would have the option to be able to get into, financial support as well. So different types of programs depend on what kind of insurance you have. So we can go to the next slide.

So this slide is really just kinda giving an overview of what different types of insurance that we typically see in the office. So if you have commercial or private insurance, you know, like UnitedHealthcare or Anthem, Blue Cross Blue Shield. So those will be considered your commercial plans. Then you have your government funded programs, so Medicare, Medicaid, TRICARE. So there are programs that are available for that. And then, also, if you don't have any insurance at all, there are patient assistance programs as well. So and we'll cover what one if whatever category you fit in in all of these, we'll cover those as well, what's available. We can go to the next slide.

So what these programs offer, typically, when you get enrolled, you're gonna, sign an enrollment form. And so this enrollment form, depending on the medication that you're being prescribed, is specific to the drug, and so it goes to that manufacturer, to the company. And they typically they need to get your consent in order to be able to reach out and to get you enrolled into their program, their support services that they have available. So, typically, there is a patient support representative. So this is a person who is on the back end, who is doing some of the research on what your insurance is, to see what is available for you. So if you have a commercial insurance, they'll let you know what's available versus your government or if you are uninsured as well. So they're looking at that on the back end. They typically will do a benefit investigation to see what your insurance covers and what support you may need. They also have people that are available to help navigate insurance.

So if you have a commercial insurance and maybe you're switching your insurance, thing questions that you wanna think about are, what is the medication gonna cover? What should I look for when I'm choosing a new insurance plan, to make sure that my medication is gonna get covered? Now they can't tell you what plans to choose, but they generally can give you a good idea as to what you should look for and what questions that you can ask. And that way, you can get a better idea of what you should be, choosing when you're, finding a new plan. A lot of educational resources. The manufacturer programs have a lot of resources and support, when it comes to giving you information about the medication itself, and some of their programs and things that they have available. And then they also offer a lot of ongoing support. So it doesn't mean, you know, as soon as you get started on the medication, then they're like, okay. We're all done, and now you're good to go. They offer this ongoing support throughout your treatment. So if you ever run into any issues, you know and I saw a little bit of the questions already. Took a little peek. But, you know, when it comes to co-pay cards and, maybe even maxing out those co-pay cards and the cost, those are questions that the manufacturer programs can look into because they can look at the amount, that the specialty pharmacy has used for your co pay savings card and give you some more insight as to what programs are available and how we can navigate that. So let's go to the next slide.

So co-pay savings cards. So let's talk about this first. So this is for a commercial or private insurance, and these co pay savings cards are gonna offer instant savings for your out of pocket cost for your medications. So these are generally set up either in the office, or you can go to the company websites. A lot of times when that

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enrollment form is sent in to the manufacturer and your signature is on there, then they're able to reach out to you to let you know that, hey. Since you have a commercial insurance, you're gonna be eligible for a co pay savings card. Once that prior authorization through your insurance has been approved, then you would likely be able to eligible to get a co pay card, which would be able to bring your co pay down to zero dollars or five dollars per dose. So just depending on what medication it is, they have different co pay savings cards. And, typically, what happens is you wanna get this card set up, and then you will give that information to the specialty pharmacy. That way, they can actually apply it to your co pay, and you would have that lower co pay.

Otherwise, a lot of these specialty pharmacies, they don't automatically apply these co pay savings cards. So it's important to make sure that you have that information and that you are confirming you know exactly how much it costs before you have that shipment set up to be delivered to your house. A lot of times what can happen is if you set up your co pay or your, prescription delivery with your specialty pharmacy and you don't find out how much it costs before they ship it to you and they don't apply that co pay card, then you could be liable for that money or how much it costs, whether it's five hundred dollars or three hundred dollars. So you wanna make sure that they are applying that co pay savings card to your co pay, and you confirm that with them before they ship it to you. And so, you know, there's definitely lots of questions. Typically, with this co pay savings card, they are going to renew. It should last you for the whole year, but there are some plans where they usually you know, there's allotted amount per year for these savings cards. So if you have any issues with it, if there if you use, you know, your co pay card and you get a zero dollar co pay for the first six months of the year and then all of a sudden it goes up, I would reach out to your manufacturer to find out what is happening and what's going on and also your office to see who can help navigate any of those issues. That's where the communication is really important, to make sure that you're able to get that low cost for your prescription. And so next slide.

So bridge programs. So this is another, program that is available if you have a commercial insurance or private insurance. These manufacturer bridge programs can provide medication usually at either low cost or no cost, until your commercial insurance covers the medication. So, really, what this is is a temporary program. The goal is that we wanna get that approval through your insurance. So on the back end, while your office is working on that appeal, for a denial, then this is the next thing where next step for you where you'd be able to get your medication, get started, and get established on therapy so that you can not have to worry about that. But in the meantime, you're getting your medication while your office is working on the denial process. So sometimes the denials, and, you know, the appeals for those denials take a little bit while little bit longer. So, you know, sometimes they can take thirty, sixty, or ninety days, to get a response back from the insurance company.

So getting started on therapy, really quickly at a low cost can be really beneficial. And a lot of times, I always like to let people know, you know, it's it's great to be able to get started, and come back in for those follow-up appointments. And now when you do, then that allows the provider to document how well you're improving and how much it's working, and we can show the insurance company that, hey. This is a great medication, and they need to continue this medication so we can continue to see the results. And a lot of times, that can really help to get a medication approved. Typically, these programs will last a year to two years. So, you know, generally, what happens is you come back in for those follow-up appointments, and now you've got great documentation and likely are able to get that appeal approved. And then you don't have to worry about, you know, staying in this bridge program. That's when you'll transition to getting it through your specialty pharmacy and going down to that co pay savings card that we had on that last slide. So that is typically the goal and how these bridge programs work. So I would definitely reach out to your office if you have questions about that bridge program or you wanna know how to get enrolled, and we'll have some links to those websites as well to get yourself enrolled. But I think it is definitely beneficial to utilize these bridge programs. Next slide.

So if you have a government funded program, so Medicare, Medicaid, TRICARE even, there are support programs available as well. So a lot of times what happens is, you know, we think about all of these commercial plans, and there's a bridge and co pay, but a lot of your other government funded plans cannot use the co pay savings cards or the bridge programs. So, the manufacturers, the people that are working in there that we talked about before, these representatives at the manufacturer company, or they call them hubs, they will help to find different support programs. So it could be a state pharmaceutical assistance program, state health insurance program, also known as SHIPS, Medicare savings programs, and then also Medicare part d has a, extra help program called low income subsidy. So depending on, what might work best for you, when they send that enrollment form in and the hub gets that information, they will look into that and and do that benefit investigation to see what is the best program that can support you, that can help you get your medication at a low cost, because that is the goal. They definitely wanna be able to figure out what's the best way to get you your medication so that you're not paying a lot of money out of pocket. Let's go to the next slide.

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So free goods. Again, this is for your government-funded program. This could be patient assistance programs that are through the manufacturers. Most manufacturers have their own programs, and they are specific to the medication. And so these patient assistance programs are generally if you have Medicare, and say if you have Medicare and your insurance, has approved it, but it's still a really high co pay, Or maybe they didn't approve it, because of step therapy or something else. If you don't have access to getting the medication, then you should be you could apply for a patient assistance program. Medicaid, same as well, and same with any other, government funded programs. Or if you do not have insurance at all, then this patient assistance program, it might be something that you want to consider. So So this is something you would need to apply for. It's generally separate from most of the other services that they're providing. A lot of times, they do have people inside the hub, representatives that can help you navigate any, enrollments and, things like that. But I would say, you know, definitely talk to your office and find out who is helping to manage you getting on your medication. But it is an income based program, so you do need to fill out the application. Sometimes they might do a soft credit check, or they might have you send in some financial information to apply for this. So it is income based. You wanna fill out this application. Once you do get approved, then you would be eligible to get free medication for up to twelve months. Generally, most of these things, they do, unfortunately, end at twelve months, but you can reapply.

So every year, you would just need to reapply or reenroll. And that's the same with those prior authorizations. Typically, they don't last longer than twelve months, so we knew need to renew all of those, checking with the insurance companies to see if maybe they might culprit, or if anything changes. Maybe you didn't have insurance one year and you decide to, get a new insurance plan, then, you might need to reevaluate that. So that's typically why they only last for about twelve months. So we would need to reenroll every single year. Next slide.

So biggest summary and takeaways here are being your own advocate. If you understand the process and understand, you know, kind of the steps that that we've all talked about, doctor Fu and Macy, you went over a lot of steps as well, but you are your best advocate. If you're speaking up and asking those questions, you're gonna be able to get those answers that you're needing. So utilizing your care team, whether it's access coordinators, the pharmacy specialist, but knowing who your team is. Before you even leave the office, the goal is to get a point of contact, know who to reach out to and ask those questions, and also find out what is that support. What is the support that the manufacturer is is providing, because they do all provide that support program, so it's really important to make sure that you are getting signed up with those so that you can know what's available. Learning the process, I think, is huge. Understanding that there is, for a specialty medication, there's likely always gonna be a prior authorization. So we wanna understand that process. Sometimes it can take a little while. So the best thing that you can do, is advocate for yourself. Come in to your appointment prepared and know that you've got, bringing a list of all of your medications that you've been on in the past and, preparing for that appointment so that you can get the best outcome, especially when it comes to the prior authorization process. But definitely taking advantage of those support programs, because that's what it's there for. It's there to support you, to help you get the medication that you need, and make sure that it's the medication that your doctor is prescribing. And then next slide.

Lastly, we have, the websites for Olumiant, Litfulo, and LEQSELVI. So if you are interested or have, you know, questions or wanna know a little bit more about those savings programs and the support, you can definitely go check out these websites. And I think there's q and a as well, so we can absolutely help answer any questions that we can.

[00:39:01]
Lisa Anderson:
Thank you all so much. That was really informative. I have a few more slides to share just to bring up, to point out some of the NAAF resources that can support people on this journey. We launched a few months ago our new treatment and insurance navigation toolkit. You can access it from the home page. It's sort of circled here down in the middle of the of the home page. You can click there to to explore, or you can go to the, main menu and go to treatments, and then treatment and insurance navigation toolkit is accessible there. There are a number of modules in the toolkit, including one that's focused on understanding insurance coverage and managing treatment access.

It has a lot of, some of the information that you're hearing here today, but also some resources like templates. If you want to, include with your health care provider a letter about your experience, with alopecia areata, there are

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temp template letters for things like that, a glossary that we linked to earlier, and just more information with step by step, what the insurance process is. And you can get to that page, with this QR code.

I also want to mention I see some questions in the q and a about insurance coverage for wigs. We are not going to talk about that specifically on this webinar because we're talking about the approved, JAK inhibitor treatments, but there is a module about getting your wig covered by insurance in this toolkit. So you might want to check that out. And then finally, if you're thinking about trying out treatment, if you're if you don't already have a dermatologist or advanced practice provider who's familiar with alopecia areata, I want to remind you that we have our doctor finder on the NAAF website. And you can go there, search by your state to find health care providers who specialize in this area. So next, I will stop sharing. And I can see everybody's face. Nice to see all of you.

Thank you for being here. Thanks for the presentations. And we will go through some of the questions that have come in. Where I can, I'm I don't think it makes a difference if I say a specific drug name. So I'll probably just say drug x because I think what we're talking about here is applicable to all of them. So this person is asking they wanna know which insurance companies cover drug x. Mindset, it was not covered. So sort of putting in that more generally, if someone is, you know, starting out on treatment and they find out, well, their their their insurer doesn't cover that drug, What are the steps for that person? And then maybe if someone's investigating insurers, if they're switching, it's open enrollment. How do they find that out? So I I've made it into two two questions.

[00:41:48]
Janelle Ball:
Generally, we've I've seen that there are, some insurance plans, of course, commercial plans that do not cover any specialty medications at all. Unfortunately, it's some it's kind of a growing trend. If that is the case, then that is what those patient assistance programs are for. So I would recommend reaching out to the manufacturer and applying for a patient assistance program. There are some where you can if it's a smaller plan, you can appeal to the employer and ask if they can add specialty medications onto the plan. I've seen that happen. I've had several patients that have reached out to their employer to say, hey, "You know, we're not covering any specialty medications." Wanted to see if they can add that on there because a lot of a lot of employers don't know. They don't realize you know, they think they're just saving money because the specialty medications are so expensive. They don't cover them, and so they can, you know, make some exceptions. So I would suggest either looking into that, see if there's an exception available. And, also, you can, maybe send an exception to the insurance plan itself as well. So I would definitely check those options. And then if those are not good options, if they don't work, then definitely reach out to the manufacturer and see if there's a way that you can apply for any of their patient assistance programs.

[00:43:08]
Jennifer Fu, MD:
And I'll jump in and I'll just say that, it's this is a quickly evolving landscape. But now that we have three FDA approved oral JAK inhibitors for severe alopecia areata, We are starting to see some insurance providers have one that is on formulary, meaning that is their preferred oral JAK inhibitor for patients to start on. And maybe, Maecy and Janelle, if you have any, input on how you've seen the insurers choose which one, because at this point, I don't think it is based on the actual characteristics of the three.

[00:43:58]
Janelle Ball:
So I don't know if it is a, you know, a cost issue or, you know, they've negotiated a better A lot of times price on it. Yeah. The negotiations with the actual pharmaceutical company is what I've seen. Or sometimes it could be just whichever one is first to market. They tend to go with with those first. But that's generally what I've seen is just kinda depends on the manufacturer. And then I think if you talk to your health care provider and it's it turns out that your insurer prefers one particular, you know, drug x, your health care provider could say, well, actually, drug x, I think, is a reasonable choice for you. I don't mind starting there since that's what's gonna get covered easily for you.

[00:44:14]
Jennifer Fu, MD:
Or your health care provider might say, you know, based on your history, I wanna stick with the one that you and I decided on originally and, we will file an appeal. And then you can take it through the appeals process

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that, Maecy and I talked about. And you can even go to an external review and have your state or, the state's designated federal entity, overturn your insurer's denial.

[00:45:10]
Lisa Anderson:
Thank you for that answer. I just wanna say that you got a shout out. Doctor Fu says Doctor Fu is the best and made the process totally painless. Anyone in NorCal should see her. So you have a fan, in the audience or probably multiple many fans.

Here is another question. I'm gonna interpret this a little bit. I've had it says scalp one hundred, but I'm gonna say salt one hundred for over sixty years and have not tried any treatments for the last thirty years. Will the lack of recent treatments be a probable cause for denial? This person is asking about Medicare coverage. But I think maybe if it's we generalize it, it could, you know, answer feel free to answer it based exactly on that question. Or, you know, somebody who hasn't been on treatment for a long time. Is that a reason?

[00:45:59]
Jennifer Fu, MD:
I think there's sort of two parts of that history that we could latch onto. So the first is whether the insurer would require you to do what's called step therapy. So that's an approach used by insurers to control prescription costs. And since these are expensive medications, you might have an insurer require providers start with a treatment other than what was originally prescribed, a treatment that is less expensive. And say, you have to go you have to prove to us that you don't respond to those, less expensive drugs before we're gonna approve this more expensive, you know, perhaps more sophisticated drug. I will say that because we haven't had very, very successful treatments for severe alopecia areata up to this point, I haven't seen as many insurers build their denial on step therapy. Maybe they're gonna start doing that in the future, but so far, that's not the main reason why they're denying. And I don't know if Maecy or Janelle wants to chime in about that.

[00:47:05]
Maecy Torres:
Yes. So, mainly, what we see is, JAK inhibitors being denied for cosmetic use are not medically necessary. We for insurances that, have the JAK inhibitors on their formula list, if you have these, SALT score, then they would normally, you know, take that into consideration. I'm seeing more denials, based on insurers saying you're not meeting that fifty or more SALT score.

[00:47:40]
Jennifer Fu, MD:
And, you know, as I mentioned, a lot of hair loss experts think that, you know, people with, you know, not quite that fifty SALT score could still be very good candidates, and qualify as severe alopecia areata in our minds. But I'm seeing more of that being a gray area where we're having to fight with the insurers and say, this is severe alopecia areata. And you need to think of that as not just that pure SALT score alone. There are many other factors that go into that. So that's where I'm seeing more, argumentation right now. There is, you know, I haven't seen this yet, and I'm I'm hoping we don't see it, but we do have, you know, some data to show that the longer somebody has had a severe episode, perhaps the less likely it is that they're gonna be, you know, a very robust responder to an oral JAK inhibitor, that data is still continuing to evolve. I haven't seen insurers deny coverage based on the length of the current severe episode yet, and I really hope they don't.

[00:49:05]
Lisa Anderson:
Okay. That that seems that's, like, it seems like a highly technical issue at this time and not there's not. There's some evidence, but not enough evidence to say that note that a person definitely would not respond. And so let's hope that that doesn't become a thing. Let me ask another question. And I don't know if you if you'll be able to answer. What's the initial denial rate for JAK inhibitors and the rate of denial upon appeal? And what approach should a patient take if the insurer elects to play the delay, deny, defend game? Do you have any do you have any sense of what the denial rate is? Is it do you do you know what I think?

[00:49:45]
Jennifer Fu, MD:
Policy? Maecy, maybe it probably has a Maecy, do you have a a sense of this? It's probably also changing.

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[00:49:51]
Maecy Torres:
Yes. So there's some private insurance that have denied JAK inhibitors last year, but we see some of them approving it for this year. And like Janelle said, if your insurance denies the medication, you can always, you know, have your doctor's office, help you with the financial support and free drug program from the manufacturer. And definitely, have your doctor's office, file for an appeal so you can get that medication covered.

[00:50:32]
Janelle Ball:
Yeah. It's hard to to say a denial rate just because every state is so different. You know, you have so many different insurance plans, and, you know, California can be completely different from where I'm at in Ohio. And, you know, we we do see denials, but I've got offices that are in Indiana and Minnesota and all different states. So it's it's hard to say what that denial rate looks like, but, you know, I think the biggest thing, the next approach would be find out, you know, if you have a commercial insurance, you know, like Maecy said, get enrolled into a bridge program, find out what that process looks like for the denial, if there is an appeal, if it you know, what that looks like. Look at the denial reason. Look at, why the insurance is denying it and use that to your advantage. So if there is a reason why they're you know, a specific reason as to why they're denying it, is it because it's they're thinking it's cosmetic, or is it because they want you to try another medication first? You know, whatever the case may be, but use that to your advantage and find out why it was denied first. And, that can kind of lead you to what your next step should be. But if you have a commercial insurance, utilize those bridge programs. Make sure you find out what what they look like, what they are, and how to get enrolled into those programs, because that way, if you get started on therapy, it's gonna be better for you because then you're gonna have more of a case when it's working. You know, when you've got it when you've already established on therapy and things are working well, it's gonna be easier to to appeal to the insurance to say, hey. We wanna continue this therapy. There's no reason to take, you know, this patient off the medication.

[00:52:19]
Lisa Anderson:
This is a related question about SALT score. So if insurers ask about SALT score, but the drug must continue to keep the hair growing, do they come back and ask for SALT scores at some frequency and then stop the approval if there's success if the success of the hair regrowth, lowers the SALT score?

[00:52:41]
Jennifer Fu, MD:
Yes. And this is very frustrating. Sometimes we do have insurers that try to do that, but we have good arguments for why, for many people, continued therapy is necessary to maintain a good response. You know, again, that, that data is also continuing to evolve, but, yes, it is true, an insurer could try to say, well, now you've improved and now your SALT score is a lot better. You no longer qualify for the drug. But I think your health care provider will have a very strong argument. If if they give you that as a denial reason, I think your health care provider would have a very strong argument for, appealing.

[00:53:26]
Lisa Anderson:
Okay. And just I think you've all said this more than once, but just to clarify, when this kind of denial comes in and it's complex like that in terms of SALT score or, you know, the the science behind the treatment, There's not an expectation that a patient on their own or parent is mounting this appeal.

[00:53:50]
Jennifer Fu, MD:
No. Absolutely not. I think the patient or parent of a patient's role in this process, other than, you know, staying on top of things and being an advocate, is to the one part where you can play a role is to provide that patient letter of appeal, especially if you've gone through several layers of appeal, especially if you're doing the external review. So I have found that submitting the patient's own letter, documenting how this has affected them, not just psychosocially, but also functionally. You know, I have a patient who, has a farm, and that's their livelihood, and nail involvement made it very difficult to handle tools. Lack of scalp hair, increases sun exposure. So for anybody who has, you know, an outdoor occupation or hobby that really can affect you functionally. So those are the kinds of argument that I had found, really, resonate, seem to lead us to, you know,

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approvals after past denials. So, I think writing your own very strong letter about how this has affected you, that's where a patient can really make a difference or a parent of a patient.

[00:55:02]
Lisa Anderson:
Yeah. Thank you. There are quite a few questions that have come in about Medicare, so I'm just going to ask one or two. I'm a bit older. If I started the JAK inhibitor at age sixty, will it no longer be covered at sixty five when I switch to Medicare? Is there any feedback on Medicare specifically? And then someone else asked, does Medicare part D cover JAK inhibitors?

[00:55:22]
Janelle Ball:
I think it depends on what your part D is. A lot of times, you know, now with all the changes with Medicare, the M3P program, if you're enrolled into that and as long as it's on formulary, then you would qualify. So a lot of times, it just kinda depends on what is on the part D plan form formulary. So if you have Medicare Advantage, you know, or whatever, if it's Humana, just wanna look at what they cover, what's on formulary for the specialty medications. Typically, if they cover it and they approve it, you might have you know, and you're enrolled into that, prescription payment program, then you would likely have, you know, that monthly payment. So if there is a high co pay for it after you've been approved, then that's when you would wanna look into those patient assistance programs to see if you would qualify.

[00:56:19]
Lisa Anderson:
Okay. Thank you. I think you touched on this a bit, Janelle, but I'm gonna try to ask this question. Someone with severe alopecia has had good results. It was only affordable to me even with insurance with one of the manufacturers' co pay assistance programs. They recently advised that my co pay assistance card's annual funding would be exhausted after my next month's refill. They suggested that I could switch over to a PTR program. Mhmm. In this scenario, I would have to pay the entire co pay myself and then submit a claim for reimbursement. Does the panel have any experience with this PTR service and if it worked out for the patients that have used it? Anyone?

[00:57:15]
Janelle Ball:
I have. So every every company, every manufacturer is different on how they approach that. Usually, that's these accumulator or maximizer plans where they basically are using all of your co pay savings card, the money for the whole entire year, you know, within a couple of months versus spreading that out. And so, typically, if you can identify it early on, that's better. That way, they can monitor how much, they're using. And, typically, what they'll do is is switch it to some companies will switch it to, a prepaid debit card. The biggest thing here is is definitely reaching out to the manufacturer as soon as you find out, if anything is happening and what's happening. That way you can kind of avoid it for the following year. You know, there's definitely these programs are they're seeing the need for it, so they're all creating programs like this to kinda help, you know, fill in the gaps. But, unfortunately, it is it's an issue that has just been ongoing. There's a lot of states that have banned it, and said, you know, they're not allowed to have these maximizer plans or accumulator plans. But biggest thing is is if you see that happening, reach out to the manufacturer. They can look into the usage of your co pay card, and offer solutions like that. But, yes, they I typically, some of them, they will have you you if you pay upfront, if you can afford to do that, then you can pay it upfront, and then they can reimburse you. Some of them, I've heard, they reimburse really fast. So it just kinda depends. You know, it unfortunately, it's it's one of those things you kinda have to look into it ahead of time and know how to kind of, get ahead of the game if you have one of those plans. Maecy, I don't know if you've seen that happen as well.

[00:59:11]
Maecy Torres:
Yes. And, also, I would like to add that if you can also call your specialty pharmacy and ask how much your insurance is paying for the medication and how much your Co-pay card is covering for that medication. So that way, if they say that your insurance only paid a hundred dollars and then the co-pay card paid five thousand dollars, then that means that, you know, it's time to call your copay card program.

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[00:59:39]
Lisa Anderson:
Okay. I'm just gonna do a few more questions. We'll go over for just a few minutes, and then we'll wrap this up. I just wanna say someone's asked the question, can we bring up the website links again? This webinar is being recorded. If you're on the webinar, if you registered for the webinar, you will get, or with the link to the recording sometime tomorrow, and we we we can include those website links in that email that you get as a follow-up to this webinar, and we will also put it on the, web page for this webinar. Here's a question.

If your insurance has a JAK on their tier drug list with co pay present for that drug tier, is it still likely for there to be a prior authorization form requested?

[01:00:24]
Maecy Torres:

It all depends on what plan you have and what formulary medications or JAK inhibitors they have under formulary. So if you're not sure you or your health care provider can call your insurance and check to see if that medication is under the formulary. Most likely, for specialty medications, it's gonna require prior authorization. So if, you know, if your provider wants to prescribe that medication, you know, the specialty pharmacy or health care professional can, check with your insurance.

[01:01:02]
Lisa Anderson:
Okay. Very good. There's a note here to remind me to mention, and maybe Doctor Fu, you can comment on this, when someone is on a medication on a JAK inhibitor, having success with the JAK inhibitor, and then they receive a denial because the there's a different JAK inhibitor on formulary that the insurer wants the patient to switch to, for not for a nonmedical reason. So nonmedical switching, and you touched on this earlier. Just to note that NAAF is opposed to nonmedical switching. We have some information about that on our treatment and insurance navigation tool kit. We'll be adding some more. But is that something in your experience that you have work to appeal that?

[01:01:54]
Jennifer Fu, MD:
Oh, yes. Yes. So, again, very frustrating, because it has nothing to do with the patient's past good response to the, in this case, the JAK inhibitor that they were on, their safe use of the medication. And so, that's why Lisa's referring to that as non medical switching. So, switching simply because the insurer, you know, has a different thing on their formulary. So yes, I have written very strongly worded letters to insurers explaining why, this is not appropriate and we're going to appeal. I will have to say, I mean, because the appeals take away so if they've just decided to stop covering, this may be an instance where, you know, we need to work with, experts like Maecy and Janelle to get the original drug in some other way for the patient while we are going through the appeals process.

[01:02:50]
Lisa Anderson:
Okay. Very good. I'm just looking maybe one one well, Janelle, I mentioned PTR before. Can you do you know what it refers to? Because I don't think I knew what the initials PTR were. There was a question about Mhmm. Reimbursement. I

[01:03:13]
Janelle Ball:
I don't know that specific term. I I mean, I know kind of what it's alluding to. They have these programs I don't know if they have a specific name for them, but, basically, it's like a a patient card where they will fill sometimes they will fill a card a credit card, with a certain amount, you know, if there's a certain amount that the, the specialty pharmacy is pulling. So if it's five thousand dollars, they'll only load enough for one fill on that card. Sometimes, you know, if you, they might request for you to pay the amount and then they reimburse you. I've seen a couple of them about, Olumiant in there. So I know that they do have programs for all of those.

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[01:03:57]
Lisa Anderson:
Okay. PTR post transaction reimbursement. Someone is is helping me. Yes. That's right. Ask the patient to pay up front and then seeks reimbursement. Thank you for adding that. I think that we will stop there. I wanna thank all of you for being here and, you know, taking the time to volunteer to share your expertise on this webinar. We know that. I I think what what we can say is to everybody out there, you're not alone. Many people are going through this, but I think it's getting better.

And don't give up. No is just the first answer, but it's not the final answer.

[01:04:04]
Janelle Ball:
And, there are support programs out there to help.

[01:04:08]
Lisa Anderson:
Any any final words before I share my …

[01:04:55]
Jennifer Fu, MD:
Have patience and be nice to all of these experts who are helping you, who care about you and want, you to have the medication that you should have. So, work with them. It is, purposely designed to be a frustrating process, though don't let it get you frustrated. We're here for you. We'll get you there.

[01:05:17]
Lisa Anderson:
Thank you for all you guys do to support the patient community, and for supporting NAAF by participating in this webinar. Okay. I'm going to share my screen, and we will wrap this up. Give me one second.

Okay. So I wanna say thank you again to Doctor Fu, Meacy, and to Janelle for being here. Thank you to the audience for being here. Please share your feedback on the webinar and help us plan plan future presentations. As you know, a short a link to a short survey will pop up in your browser window at the end of the webinar and your feedback is greatly appreciated. Join us for our next webinar Makeup Skills for Alopecia Lashes, Base, and Contour with Confidence. This is a subject that's back by popular demand. Proud members of the alopecia areata community and featured presenters at the NAAF conference, Keya Trammell and Abby Andrews are hosting this hands-on skill building webinar. Whether you're just starting out or refining your routine, join us to learn how to apply lashes, select and blend foundations, and contour with ease using techniques tailored specifically for individuals living with alopecia areata. This webinar will take place on Wednesday, September 17 at 7 pm Eastern and 4 pm Pacific, and you can register now using the QR code here.

And I also want to remind you that the Walk for Alopecia is coming. Doctor Fu is our leader in San Francisco. Thank you for supporting that in that way as well. The third annual walk for alopecia is gonna take place on Saturday, September 27th. It's bigger than ever. We will have two flagship sites, one in San Francisco and one in Philadelphia, and more than twenty volunteer led community walks that are happening from coast to coast. Anyone anywhere can walk as a team or as an individual. So please join us for the walk and register today. You can scan this QR code or go to naaf.org/walk for more information.

And, as you've heard me say before, there's a lot happening at NAAF. You can keep up by scanning this QR code, joining our email list. You'll receive regular updates on alopecia areata news and research, the monthly electronic newsletter, and notices about upcoming webinars and other events. And don't forget that NAAF offers a number of resources and programs to the alopecia areata community, including support groups, our youth mentor and legislative advocate programs, the Doctor Finder, clinical trial listings, as well as our annual conference. So we hope you will continue to join us on activities like this. And this concludes today's webinar

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program. So thank you all for joining us. Thank you to the wonderful speakers for for being here, and we look forward to seeing all of you on the next webinar. Okay. Have a good evening. Bye.

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*Please Note: This transcript was created using AI tools and might have minor inaccuracies or misspellings