

Hello and welcome everybody to the podcast. I'm Korey Capozza with Global Parents for Eczema Research and our topic today is topical steroid use in children. Now I'm pleased to welcome today's guests

First is Dr. Steve Feldman. He's a board certified dermatologist and skin pathologist at Wake Forest School of Medicine in Winston Salem, North Carolina. He studies patient's treatment preferences and treatment adherence for skin conditions, including eczema. He's also served on the American Academy of Dermatology's Atopic Dermatitis Treatment Guideline Committee.

We also have Kathy Telos. Kathy is a registered nurse and the president of the International Topical Steroid Awareness Network, or ITSAN and she's the parent of a child that suffered from topical steroid withdrawal after using topical steroids for eczema.

And we also have Jeff Kastner. He is also the parent of a child with eczema who found success, treating his child with a combination of cream, topical steroid and antibiotic. He is a parent advocate for this treatment. And he attended our patient focused drug development meeting in 2019 called the More Than Skin, Deep meeting to share his experience.

So Dr. Feldman, Kathy and Jeff, welcome to the podcast.

Thank you.

Thank you

Good to be here.

I want to first acknowledge that our topic today is controversial in our community. But we want to tackle it head on with a thoughtful discussion, because oftentimes that doesn't happen. We just retreat to our silos, but it generates a lot of concern and anxiety among caregivers.

Um, it can help eczema symptoms, but the effectiveness can decline over time. And a lot of people report that it's hard to wean off of them once they start. And then of course there are side effects that we hear about. So, Dr. Feldman, I wanted to start with you. This treatment has been around for eczema for over five decades now. So you know, they've been in the field. People have been using them, help us understand what we know about effectiveness and safety in kids and what we don't know.

Yeah the body's making steroids all the time. When we use them topically more often than not probably there's not enough absorbed to have any internal effect.

There was a nice review that looked at but long-term studies had been done and they didn't find any worrisome side effects of long-term topical steroids. But we know that if you use potent topical steroids long enough, it could thin the skin out a little bit. Low and medium potency and see topical steroids for atopic dermatitis, clear the rash up fast and have, basically no side effects in the short run.

Thank you for that overview. I wanted to ask though, because I think this is where parents have concerns. There haven't been a lot of long-term studies, especially those that look at kids.

What patients and parents talk about is they use the topical steroids, they get clearance, but as soon as they taper it comes right back. They end up using them on their children long-term and without cessation effectively. In that population if it's really extensive, severe disease, they may be, they need some topicals for their worst spots, but they may need something like dupixant or a phototherapy or some other systemic therapy for control of their condition.

Yeah. Jeff, Cathy, any follow-up questions here?

What's difficult is they're approved for short-term use, but they're used on chronic conditions like eczema. We really don't know how long is too long and so I think that's where the problem is.

With my son, he was burning and stinging on treatment. I didn't mistrust this drug. I'm a registered nurse. So I think I fully know how to execute treatment plans. We were fully adherent and did properly treat. So it's been a really crazy journey to try to figure out why he's rebounding so severely and when you're communicating that it's not working and not just not working, making things much worse, sometimes doctors don't think that you're adhering to your treatment you are.

Topical steroid withdrawal syndrome is a new emerging diagnosis. It's controversial, but it's being published on more. We finally decided to, to see what happens if we stop using Steroid you know, we had treated him for three and a half years. With my son It took about 18 months for him to fully clear up. We then did patch testing to see if maybe he was allergic to that steroid and he was not. Members of our support group do clear up over time after ceasing use of steroids. This does not happen to everyone on steroids, but for the people who it does happen to, they should be aware and be able to recognize it.

Yeah, on that point, Jeff, you've had great success with longer term steroid treatment for your son in combination with a topical antibiotic.

Absolutely. Yeah. Yeah. My son was covered head to toe. The dermatologist basically prescribed steroids. Every time and it did absolutely nothing. So they went to oral steroids, and oral antibiotics, they would clear it for seven to 10 days. We come off of that and then it got worse every time. So that's when I found Dr. Aron. And contacted him and he said, Hey there's a *Staph* element here that's not being treated. So even when you use steroids with this, you're basically reducing inflammation. You're putting on Vaseline. So the *Staph* is increasing. And he said everywhere, you've got red, that's really bad *Staph* bacteria. He prescribed topical steroid with a topical antibiotic explaining that addresses the *Staph*.

And he told me it has to be ongoing. He said seven to 10 days Isn't enough to treat severe eczema, especially with *Staph* bacterial infection. We put that on. The very first night in five years, my son's slept through the night for the first time. And the second night was even better.

And I just, I couldn't believe it. So I kept that up daily for the full year. And now he hasn't used it in several years.

Yeah. Thanks for sharing. It's really interesting. Here's three parents with such different experiences with topical steroids and I'll share my son, went down both of your paths and didn't have a resolution of symptoms with either of them. So to me, it points to the remarkable heterogeneity and the atopic dermatitis community.

So Dr. Feldman, can you talk about this phenomenon that so many parents observe, which is they're taking the topical steroids as instructed, but they're not working or they stop working.

Yeah, when it comes to adherence, the great majority of people who have been prescribed topical medicine are not putting it on as directed. And we know this from studies that put computer chips in the caps of the containers and record the day in time people open and close the containers and in their diaries, they say, we put it on twice a day, but the computer chips report that they're not putting it on. Maybe the reason why they're not putting them on as much, just because they're not seeing the benefit of the steroids. Usually it works the other way. Topical steroids are so effective that people quickly stop using them because their child is getting better.

One of the studies we did took people with eczema who had failed topical steroids. And we put them on topical steroids, under conditions designed to get them to use them. And in this very small study, everybody got better.

Is it possible, there's some people whose genetic predisposition is so strong that they don't respond to topical steroids. Yeah.

You make a really good point that people aren't adherent and yeah, this is complicated, a parent goes into the doctor's office with a young child who has moderate to severe eczema everywhere. And you leave with five prescriptions all with different steroid potencies, telling you to put it here for this amount, then taper this step up this step down. It's really complicated. And I do think it is hard for people to be adherent, you've been up with your itchy child all night and suddenly you've got this complicated regimen. We don't give any support to parents and patients, oftentimes outside of that visit,

Yeah, one thing I want to make really clear. I never blame the patient. I haven't done what I need to do to support them. Giving patients five different things to do, I think is ridiculous. And it's not the patient's fault. Even the whole practice of medicine, here's a prescription. I'll see you in two weeks. It's ridiculous. If a piano teacher said, here's your sheet music, I'll see you in two months, nobody would expect that, that next visit would sound very good.

Right? Yeah, for sure. These communities of patients that we're talking with are not small. The community that Jeff was referring to they join because they're not having success with straight up topical steroids. Usually that's like a 70,000 patient community,

We're over 80,000

And Kathy's group is very large too.

We're in the tens of thousands.

So it may be, not the majority of patients, but these are a large number of patients that are struggling to find solutions on conventional therapy, which is typically topical steroid use.

if you have extensive total body disease, I'm not sure a topical therapy is a practical solution, right? From the get-go. So I would not expect people to be adherent. But if, we're talking about are topical steroids safe and effective for somebody who has relatively limited disease that they can put topicals on. Yeah. It's generally safe and effective for that.

Yeah, and I think it's a fair point, are these the right treatment for a moderate to severe patient that's really covered? .

Now we're on the precipice of this new age of treating. Is this even going to be the main issue moving forward, now that we have all these new topicals and new systemics and biologics coming on the market, and the journey that we had with our kids is not going to be the issue.

I hope so. This is really opening new doors to just being able to listen because you have something else to offer.

Do I feel that topical steroids will become less the treatment? I don't believe that at all. I think The vast majority of cases of eczema are just exiting without these problems that people in this group have experienced. Topical steroids probably takes care of that in most cases.

Yeah,

A lot of parents and patients have found success combining steroid with antibiotic when they didn't see the same degree of success with just steroid. Why would this combination be the key to seeing resolution of symptoms?

Eczema can look like it's infected and maybe sometimes it is infected. If there's infection there, it should be treated. I had the impression that if I gave people a little antibiotic could help, but the clinical trials haven't been terribly supportive of that conclusion.

My son did have antibiotics orally two weeks out of every month for a year. When he was on antibiotics his skin looked amazing. I do think a clinical trial is warranted for the treatment that Jeff mentioned so many people using it. But it just has not been studied.

I want to get to some parent questions here Joseph from Puerto Rico asks, are there lab tests that can measure how much steroid goes into the body. And are there clinical criteria to determine if you've had too much exposure .

Yeah. In theory, blood test could measure how much steroid is in your body. I've never seen in my 30 years of dermatology a case but I bet it happens. It could be a rare event, but if somebody were to take our strongest steroids like Clobetasol, and use them continuously for a month or two. Yeah. I think it would have enough effect to be detectable.

It's simple way of monitoring. That is they measure your height. That's why my son he was referred to an endocrinologist.

Yeah, we, We had the same experience. We got referred to the endocrinologist. Our endocrinologists could actually show us how he was charting my son's growth year after year, because: Is it possible? Steroids are stunting his growth? And he said, no, it's not. Here's why. We don't see any significant alteration in this graph when he started the steroids he said, if your son's got full body eczema, what you did for him is far better. Then daily stressors all through your body, that's going to contribute to that problem a lot more.

Yeah. Jeff, I think that you raise a good point.

I don't think you can use a growth chart in a simple way to assess the steroids because the eczema can affect the growth as well. I, it wouldn't surprise me if some children with severe atopic dermatitis who have poor growth from their atopic dermatitis, if they get their disease cleared up with a little bit of topical steroid use they might start growing. Not to discount Kathy's anecdote. Again, different people, there may be different issues going on.

I think that's why it's important to go to the endocrinologist because they can do tests to rule out what is going on.

Yeah. And it's a good point too, because these kids aren't sleeping and that's when growth often happens.

Debbie in the UK asks how can patients avoid getting stuck in a cycle of use where the eczema returns aggressively, as soon as you stop. And Debra in Chicago asks, should patients be on topical corticosteroids for years on end without break? How do you avoid getting in this pattern of continual use? Because you effectively can't stop using the steroids without a terrible flare.

If it's covering 30%, 50%, 80% of the body. You could try topical steroids and the disease stays gone. Great. but if stops, as soon as you stop therapy, it's time to add either phototherapy generally, or a little low dose methotrexate, possibly cyclosporin or nowadays, if you're, age six months and over, you can get dupilumab approved. I think it's safer than some of the older drugs.

I think it's really important to acknowledge different patients have different experiences, not just with eczema, but also with treatments there's no one way to treat this condition.

For mild cases topical steroids can work really well.

But, when you start getting into those more severe cases and they're not working well, it's time to find something else and thankfully we now have some new options. Adherence is a challenge. I think there's a lot of reasons for that. In reality, people are using topical steroids differently than how they're usually prescribed. And we still have a lot to learn. It can be challenging for parents and patients when they don't see the results. And they're hearing about side effects. And maybe they're not using enough. And so therefore they're not seeing the results they want to see. One advantage of the Dr. Aron regimen is that it's super simple.

For sure, parents and patients need more support with this. So we need better ways of supporting our patients with managing this complex disease. So with that I think we should wrap up. Great discussion and thank you for being part of the podcast.

Great discussion guys. Enjoyed it. Thank you.

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In part two of our episode on topical steroids. We're going to examine the research evidence for their use. This interview was recorded separately at a later date.

So welcome to the podcast. Joining us from the United Kingdom is Sandra Lawton. She is a dermatology nurse consultant and clinical lead at the national health service. Sandra has worked in dermatology for 34 years and been instrumental in setting up the award-winning clinical service for children with eczema and the Nottingham support group for carers of children with eczema. Sandra is also a contributing author on the 2022 Cochrane review article entitled. What is the best way to use topical corticosteroids to treat people with eczema, which assessed and summarized 104 studies on topical steroid use for eczema involving 8,443 people.

Sandra w

Welcome to the podcast. Thank you.

Sandra. I wondered if you could walk us through some of the key findings of the Cochrane review.

The Cochrane review identified that you need to have two treatments work well, and that is your ?, which is the main state of everybody with eczema and should continue even when the eczema was well controlled and using topical steroids effectively and safely.

It's important that when eczema flares you have the correct potency of steroids to gain control, then once that's clear you need to then use the steroids two days a week in the future to prevent flares.

Using this, two days a week to keep control of the eczema, showed no evidence of any skin thinning. And it's very effective major team for children and young people that have those hotspots of stubborn eczema that constantly flare.

Can you say a little bit more about this preventive approach? So you use the adequately potent steroids to clear up that flare, but then you continue two days a week to use the steroid to keep that flare under control.

Is that something that people with more severe eczema need to do indefinitely to keep those hotspots from coming back?

You can use the twice weekly regime for one or two months. And if they're not flaring, they can leave it off. For some young people it may be better treating the flares when they flare. But for a majority of young people, we do find that it works very well.

I think parents are equally preoccupied with the adverse events. Did you find from the Cochrane review of these a hundred, some odd studies about those adverse effects? And what do we still not know?

There was no evidence from the Cochrane review of any skin thinning or problems with using the steroids twice a week. Side effects and problems with steroids when steroids are used for long-term on body sites where the potency is too strong or there's consistent overuse of products.

There's lots of misinformation around topical steroids, but in clinical practice, we don't routinely see side effects. In my 30 something years of dermatology, I think I've probably seen one episode of systemic absorption. And I've seen a few thousand children over the years.

The benefit is your child's eczema will be under control. It will improve their quality of life. They will sleep better. They can participate in activities. So the review did show that topical steroids are safe. And it's important to treat and prevent flares of eczema safely and effectively with the topical steroids alongside, using ?emollients.

Thank you. And I think that one thing that does happen with the more severe eczema is you never quite get to that point where things clear up. And so sometimes people escalate and potency of steroid goes up. And that's where we see people maybe getting in the cycle of inappropriate use for they're using too much potency steroid for too long. When somebody can't gain control of a flare like that using topical steroids, are they at that point, really a candidate for other treatments?

It's a very holistic approach to managing young people and children with eczema, because there's so many variables, for example, w What things in the environment to triggering a flare of the eczema? What products are they using?. And once you've revisited how they're using it and taught them how to treat effectively, then the Sol treatment options but it's a continuum. It's a stepped approach to managing eczema.

You talked a little bit about this balance that I think parents are trying to strike. I know I always was, which is trying to minimize overall exposure to steroid, particularly in a young child where there's so much body surface area involved with clearing the eczema.

You've got to balance using a lot more of a weak or one for longer without building in a break versus a short, sharp burst of something a bit more potent and gaining that control. So we have to look at the impact, the eczema's having on sleep, school relationships, friendships, if they're getting infections.

Often patients have recurrent infections and you have to treat the eczema to prevent infection. I always say to families if you've got poorly controlled eczema and they're getting me to come into infections, it's because the bacteria is having a party in that eczema skin. You may need to step up for short bursts to get that control because you're not treating normal skin, you're treating thick eczema. So that's why you need to feel it as well as. Because that will tell you.

When you say feel, do you mean how it feels texture wise.

Treat the eczema too. It feels normal so compare site where there's eczema to the normal skin and you want it to feel normal and ?. Okay. Often people stop too soon. You need to keep going a few days after it looks less thicker and it feels.

And Ensuring that they still use emollient. There's often a concept or my skin was better. Now. I don't need to use my moisturizers. Whereas you moisturize to protect the skin and.

The Cochran review it sort of states in the summary that most studies were really quite short term. But what about long-term and what additional studies are needed?

Yeah. I think the review does show that It's constant persistent use without a break, That's when you're going to start running into a problem. And so you need the right strength to give control and then build in breaks. The skin recovers, and you're not going to get the side effects. There's always going to be more need for more research and studies,

Okay, so here you're talking not just about the Cochrane review, but your experience in clinical practice, integrating, the both, because there really haven't been hardly any studies looking at steroid use over the long-term. As I understand it,

and that's why the Kaka we've used it quite useful.



## Cochrane Review

Yes. And what I appreciate about the Cochrane review it's very helpful to understand what the body of evidence can speak to and what it can't speak to.

In part, what I take away from the most recent Cochrane review is there really wasn't much there about unwanted side effects. Over the long-term, they came largely from low and very low certainty short-term trials. So I think it is fair to say that there is more research that needs to be done there.

I wanted to talk about a couple of questions that came from the parent community. And one person asked, can people become addicted to steroids and experience withdrawal when they start.

In clinical practice, with children, I've never seen that. And my colleagues would probably agree with that.

Do we know anything about the precision medicine approaches is matching the right patient with the right treatment related to steroids.

I think in that scenario that would probably need further research.

I wanted to just mention the conclusions of the Cochran review. The summary said that overall, we are moderately confident on the effectiveness of steroid creams to treat eczema, but we have little confidence in results on unwanted effects because studies were small and did not always use the most reliable methods. Potent and moderate topical steroids are probably more effective than mild topical steroids, primarily in moderate or severe eczema. However, there is uncertain evidence to support any advantage of very potent over potent topical steroids. Effectiveness is similar between once daily and twice daily or more frequent use of topical steroids to treat eczema flare ups.

You don't need to do it twice a day that and get the same effect. And I think parents will be really relieved to hear that because they're more often wanting to reduce the amount of steroid use.

Various products they use twice daily, but I only ever use steroids once a day. Once a day, you're going to use it more effectively. And the evidence has shown that

I think that's such a helpful finding. And then the review states that topical corticosteroid weekend therapy. So just those two days a week is probably better than no topical steroid use or reactive use to prevent recurrence of eczema or relapsed to flare ups. I have not heard that before. It's an interesting point.

I've been using that method for many years. Yeah. It is very effective of getting control and if you can keep control with two days a week, that makes a huge difference to your life and their life. And obviously reduces risk of flare ups and having infections, et cetera.

Yes. With those hotspots that keep coming back. Maybe they just take a lot longer to heal and so they do require constant attention for a longer time.

Final two paragraphs of the summary say adverse events were not well reported and came largely from low or very low certainty short-term trials in trials that reported abnormal skin thinning frequency was low overall and increased with increasing potency.

And finally the conclusion said we found no trials on the optimum duration of treatment on the flare, and no trials on time to leave between application of topical steroids and emollients. And then finally it concludes that there is a need for longer-term trials. So I think these are really important points and certainly ones that resonate with me.

Thank you

One thing I do take away from our conversation with you today is there's an art and a science to it. And I appreciate you bringing both perspectives of the Cochrane review, but also insights from your work in the clinic with patients day to day. But Sandra much for joining us on the podcast. Thank you