



National
Eczema
Association

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NEAMagazine

Research, Support and Education for Those Affected by Eczema

My Experience with Step Therapy

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Founded in 1988, the National Eczema Association (NEA) is a 501(c)(3) nonprofit and the largest patient advocacy organization serving the over 31 million Americans who live with eczema and those who care for them. NEA is supported by individual and corporate donations. Advertising is accepted for publication if they are relevant to people with eczema and meet certain standards. NEA Magazine provides health information from a variety of sources, but this information does not dictate an exclusive treatment course and is not intended as medical advice. Persons with questions regarding specific symptoms or

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Letter from the Editor



Spring is in full swing! As we await our new CEO during this season of growth and transition, I'm thrilled about the abundance of exciting updates we have to share with you.

Virtual Hill Day, our third annual event dedicated to eczema advocacy, is coming up this May 7–8. Each year, NEA Ambassadors participate in this exclusive opportunity to meet virtually with U.S. legislators to spread eczema awareness and advocate for improved access to care and increased eczema research funding. Learn more about how to get involved on page 3.

In the meantime, you can also read about NEA Ambassador Edward Taguba's experience with step therapy, a common access issue many eczema patients experience, on page 16. His story sheds light on a barrier to eczema care that many of our own community members continue to face and fight to advocate for better solutions.

As the weather gets warmer and the days grow longer, there's more time to dedicate to springtime activities that offer a breath of fresh air in more ways than one. Read about our wide range of eczema-friendly tips to spring clean your space on page 13, as well as how the amount of water you're drinking each day can affect your eczema on page 25.

And finally, don't forget to register for Eczema Expo 2024! We're counting down the days until we meet again, this year in Denver, Colorado from June 27–30. Until then, happy spring from all of us here at NEA.

Warmly,

Amber Whiteside
Editorial Director
VP of Marketing and Communications

Our Mission: NEA is the driving force for an eczema community fueled by knowledge, strengthened through collective action and propelled by the promise for a better future.

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NEA NEWS

Our Latest Updates

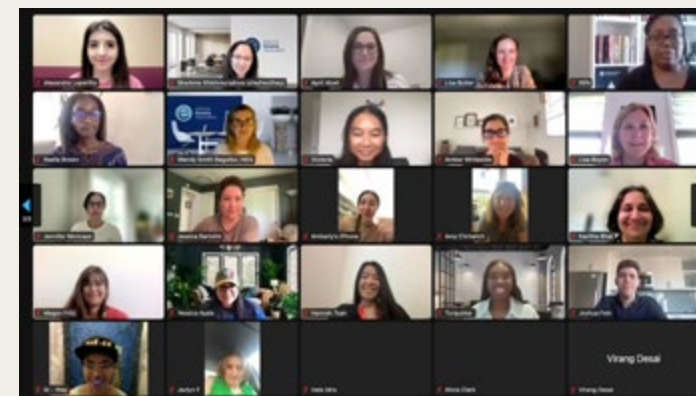
Lobbying for eczema

The National Eczema Association (NEA) is headed to Capitol Hill for our third annual Virtual Hill Day. Held this year on May 7 and 8, Virtual Hill Day is an exclusive opportunity for NEA Ambassadors to meet virtually with legislators to spread eczema awareness and advocate for improved access to care and increased eczema research funding.

Join NEA Ambassadors to participate in this exciting opportunity to speak directly with your legislators. And if you're not involved with Ambassadors, you can still help us advocate for eczema.



Scan the QR code to sign up for advocacy updates. You'll receive timely and important opportunities to advocate with NEA.



Virtual Hill Day Team 2023

You can make eczema research possible!

May is Itching for a Cure (IFAC) Month — the time when the eczema community answers the challenge to raise money for eczema research.

All month long, we'll be raising donations to fund NEA's Catalyst Research Grant. This grant award gives an early-career scientist the initial funding to establish a promising line of eczema research.

And once we fund the \$50,000 grant, Dr. Peter Lio — eczema champion ecz-traordinaire — has committed an additional \$20,000!

There are three easy ways to participate in IFAC:

- 1. Create your online fundraising campaign by becoming a Cure Captain.** Register, set your fundraising goal, share with your networks and start raising money to end eczema!
- 2. Host a fundraising event on May 18, the IFAC Day of Action.** Although, it's totally OK to fundraise on another day if that's what inspires you. Dream up your favorite fundraiser. Maybe it's a walk or cycling event, a bake sale, garage sale, bowling night, happy hour, a chili cookoff — the possibilities are endless!
- 3. Donate to another Cure Captain's campaign.** Visit our website to find active IFAC campaigns that you can easily donate to online.

We "Itch for a Cure" for all people affected by eczema, including people like Camber Taylor, our Itching for a Cure Hero, featured on page 18.

Together, we can fund essential eczema research and come closer to our shared vision of a world without eczema. Get started at ItchingForACure.org.



Camber Taylor

The Seal of Acceptance™ expands into lip care and deodorants

In January, NEA announced the addition of lip care and deodorants to the product categories eligible for the Seal. Existing product categories include moisturizers, sunscreens, cleansers, disposable wipes, haircare, over-the-counter drugs, household cleaning and laundry.

For people with eczema or sensitive skin the search for personal care and household products can be triggering in every sense of the word and the Seal continues to expand into new categories in order to make it just a little easier to find suitable products not just for eczema but for a life with eczema.

The eczema community — and those with sensitive skin — can expect to see new lip care and deodorant products awarded with the Seal as soon as fall 2024. Visit [EczemaProducts.org](https://www.eczemaproducts.org).

NEA receives Engagement Award from PCORI

NEA has been approved for a \$250,000 funding award through the Eugene Washington PCORI Engagement Awards program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI). The award will support a project titled “Paving the Way Towards Meaningful Partnerships: Fostering Regional PCOR to Enhance Eczema Outcomes.” The award period spans two years, from Feb. 1, 2024, through Jan. 31, 2026.

As the list of FDA-approved eczema treatments grows, the need for patient-centered research to support informed decision-making and direct future research investments is becoming increasingly important. NEA’s PCORI-awarded project will promote the continued engagement of patients as research partners.

Specifically, the project will entail the formation of six regional research hubs comprising groups of patients, caregivers and researchers who will work together consistently over the project period through a combination of in-person and virtual meetings. Eczema patients and caregivers will partner with researchers to identify the greatest needs and priorities for eczema research topics and help design engagement frameworks.

NEA Ambassadors' Corner

Mega influencers in eczema

In early 2024, a group of NEA Ambassadors participated in our Corporate Council meeting. This meeting brings together pharmaceutical companies, people with eczema and NEA leadership to try to improve eczema care and treatment options.

During the meeting, Ambassadors shared their personal experiences with eczema. They spoke about what living with eczema is like for adults 65 and older and what it’s like to manage eczema when you don’t have a regular healthcare provider. The Corporate Council meeting is a direct way for pharmaceutical companies to understand the reality of living with eczema from a patient perspective to influence their research and work.

We want to share a huge thanks to our Ambassadors who continue to volunteer to share their personal experiences and insights with treatment developers. Your efforts help to improve eczema care and treatment options for the larger eczema community.

Share your voice
in a way that matters.

Join NEA
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Learn more at
[NationalEczema.org/
ambassadors](https://www.NationalEczema.org/ambassadors)



FDA-approved for ages 6 months and up
with uncontrolled moderate-to-severe eczema

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- Clearer skin that lasts**
- Not a steroid or immunosuppressant

*At 2 weeks, 18% of adults on DUPIXENT + topical corticosteroids (TCS) had less itch vs 8% on TCS only.

**At 16 weeks, 39% of adults on DUPIXENT + TCS saw clear or almost clear skin vs 12% on TCS only. 22% saw clear or almost clear skin at 16 and 52 weeks vs 7%, respectively.

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INDICATION

DUPIXENT is a prescription medicine used to treat adults and children 6 months of age and older with moderate-to-severe eczema (atopic dermatitis or AD) that is not well controlled with prescription therapies used on the skin (topical), or who cannot use topical therapies. DUPIXENT can be used with or without topical corticosteroids. It is not known if DUPIXENT is safe and effective in children with atopic dermatitis under 6 months of age.

IMPORTANT SAFETY INFORMATION

Do not use if you are allergic to dupilumab or to any of the ingredients in DUPIXENT®.

Before using DUPIXENT, tell your healthcare provider about all your medical conditions, including if you: have eye problems; have a parasitic (helminth) infection; are scheduled to receive any vaccinations. You should not receive a “live vaccine” right before and during treatment with DUPIXENT; are pregnant or plan to become pregnant. It is not known whether DUPIXENT will harm your unborn baby. A pregnancy registry for women who take DUPIXENT during pregnancy collects information about the health of you and your baby. To enroll or get more information call 1-877-311-8972 or go to <https://mothertobaby.org/ongoing-study/dupilumab/>; are breastfeeding or plan to breastfeed. It is not known whether DUPIXENT passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Especially tell your healthcare provider if you are taking oral, topical or inhaled corticosteroid medicines or if you have atopic dermatitis and asthma and use an asthma medicine. **Do not** change or stop your corticosteroid medicine or other asthma medicine without talking to your healthcare provider. This may cause other symptoms that were controlled by the corticosteroid medicine or other asthma medicine to come back.

DUPIXENT can cause serious side effects, including:

Allergic reactions. DUPIXENT can cause allergic reactions that can sometimes be severe. Stop using DUPIXENT and tell your healthcare provider or get emergency help right away if you get any of the following signs or symptoms: breathing problems or wheezing, swelling of the face, lips, mouth, tongue, or throat, fainting, dizziness, feeling lightheaded, fast pulse, fever, hives, joint pain, general ill feeling, itching, skin rash, swollen lymph nodes, nausea or vomiting, or cramps in your stomach-area.

Eye problems. Tell your healthcare provider if you have any new or worsening eye problems, including eye pain or changes in vision, such as blurred vision. Your healthcare provider may send you to an ophthalmologist for an eye exam if needed.

Joint aches and pain. Some people who use DUPIXENT have had trouble walking or moving due to their joint symptoms, and in some cases needed to be hospitalized. Tell your healthcare provider about any new or worsening joint symptoms. Your healthcare provider may stop DUPIXENT if you develop joint symptoms.

The most common side effects in patients with eczema include injection site reactions, eye and eyelid inflammation, including redness, swelling, and itching, sometimes with blurred vision, dry eye, cold sores in your mouth or on your lips, and high count of a certain white blood cell (eosinophilia).

Tell your healthcare provider if you have any side effect that bothers you or that does not go away. These are not all the possible side effects of DUPIXENT. Call your doctor for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Use DUPIXENT exactly as prescribed by your healthcare provider. It’s an injection given under the skin (subcutaneous injection). Your healthcare provider will decide if you or your caregiver can inject DUPIXENT. **Do not** try to prepare and inject DUPIXENT until you or your caregiver have been trained by your healthcare provider. In children 12 years of age and older, it’s recommended DUPIXENT be administered by or under supervision of an adult. In children 6 months to less than 12 years of age, DUPIXENT should be given by a caregiver.

Please see Brief Summary on next page.

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RESEARCH

Can I Stop Taking Medication If My Atopic Dermatitis Symptoms Are Not Bothering Me?

By **Jodi L. Johnson, PhD**, research assistant professor of pathology and dermatology at Northwestern University

Atopic dermatitis (AD), a type of eczema, is a chronic relapsing skin disease that can persist throughout life. Many AD patients must take medications for very long periods of time to keep disease symptoms under control. After being on long-term medications, patients with AD might experience clearing of their symptoms and an improved quality of life. Naturally, this leads many patients to ask, "Can I stop taking my eczema medications? I'm feeling better."

This is a complicated question with a lot of factors to consider. The answer may depend on a number of considerations including the type of medication or medications you're taking, dosage, disease stressors, flare frequency and intensity, plus other health factors. There is very little research to date around going off AD medications once symptoms are well controlled or stopping treatment altogether. In this article, we will explore the research around drug tapering, or taking a drug holiday, from certain types of AD medications and dive into what we do know.

How healthcare providers assess drug treatments

Drug treatments for AD range from topical (applied on the skin surface only) to systemic (swallowed or injected into the body).¹ Drug options for treating AD have expanded tremendously in the last several years. As new medications were approved by the Food and Drug Administration (FDA), new clinical guidelines based on results of clinical trials and other evidence were also developed. These guidelines or recommendations give healthcare providers a framework for disease care and help them consider how to use new therapies most effectively within their larger treatment toolbox. These guidelines help clinicians decide which AD therapies are right for each patient.²⁻⁶

Part of the concept of these clinical guidelines is that AD treatment exists on a ladder, meaning the strength or type of treatments can move up and down the ladder depending on severity and burden of disease, and what other medications are being taken or possible side effects.² For example, this could mean moving a patient's treatment up from topical medications to include systemic medications. These guidelines also help clinicians choose between different types of drugs like JAK inhibitors (JAKi), biologics or other treatment approaches. They also provide guidance on how long to stay with one treatment to see benefits.²⁻⁶

This flexible approach to treatment helps clinicians make recommendations and encourage their patients to work with them to make decisions for their care. Along these lines, when AD patients of Dr. Peter Lio, dermatologist and clinical assistant professor of dermatology and pediatrics at Northwestern University, ask him if they will have to take systemic medications forever, he tells them, "Nothing is forever."

"Our goal is to get good, durable improvement for a number of months, and then we can try to decrease the dose or wean from the medication," said Dr. Lio, who is also the co-founder and co-director of the Chicago Integrative Eczema Center. "Sometimes we can switch medications, which we call rotational therapy. This gives your body a break from one type of treatment and opens the door to even better improvement or possible remission with another agent. In the past there were not a lot of treatment options, but now we have a much broader palette of therapies to choose from!"

"Our goal is to get good, durable improvement for a number of months, and then we can try to decrease the dose or wean from the medication." ~ Dr. Lio

Knowing what patients consider the most important end goals for AD treatment also helps physicians discuss the best treatments to achieve patient goals and then work with patients to weigh

the treatment benefits with its risks. "I try to go through a shared decision-making process with my patients and their families before starting any medication and at each follow up," said Dr. Lio. "We talk about risks, benefits and long-term goals, and how they fit into their goals and concerns."

Some studies have also revealed what AD patients consider to be the most important disease symptoms they want treatment to improve. For example, a study of 1,619 AD patients in 2020 revealed that over 90% of these patients considered the following treatment outcomes to be very important: freedom from itching, no longer experiencing a skin burning sensation, rapid improvement of skin symptoms, regaining control of disease and being pain free.⁷ A report of patient perspectives when working toward symptom relief disclosed patients' top concerning symptoms included itch, condition and appearance of skin, sleep disturbance, anxiety and depression and reducing associated health issues like infections.⁸

Which medications AD patients use also depends on their personal risk factors and the other types of treatments in their treatment regimen. "The choice between adding a systemic medication vs. using topical medications depends on your risk factors, preferences, severity of disease and availability for regular laboratory tests," said Dr. Vivian Shi, dermatologist and associate professor of dermatology at the University of Arkansas for Medical Sciences. "You should also relay to your healthcare provider your history of eczema, other illnesses that you are treating with other medications and whether you are planning on becoming pregnant or breastfeeding."

Research and guidelines on tapering or stopping medications

In addition to all these factors, there have been several recent studies to try to develop guidelines and best practices for tapering or stopping AD medications. Here is what is currently known about these approaches for topical therapies and systemic treatments, such as oral JAKi and dupilumab.

Topical treatments

Topical treatments must be carefully used according to treatment recommendations to achieve clearing of symptoms, but it's generally easier to increase, decrease or change the strength of the topical being prescribed to control AD compared to systemic medications.⁹ For mild and severe AD, clinicians may suggest a proactive management technique using topical steroids. This involves initial application of corticosteroids twice a day for a few weeks, then reduction to once a day for a few weeks, then continued use of a mid-potency topical treatment two to three times a week indefinitely to maintain clear or almost clear skin. Topical therapies can be increased or changed during flares and used aggressively for a few weeks before then returning to a less potent topical treatment for maintenance.⁹

If AD is undertreated and not well controlled, then it is not advisable to reduce or stop topical treatment. "We must be careful since

medications like steroids, if decreased too abruptly, can cause a rebound in symptoms, sometimes making things even worse than when they were started,” said Dr. Lio. “A cautious and gentle approach to changing, reducing or stopping [topical] medications is needed.”

Dupilumab

Several studies have examined tapering or withdrawing from dupilumab once symptoms are well controlled.^{11–14}

One study in 2020 looked at reducing the frequency of dupilumab dosing after long-term disease control with dupilumab, randomizing patients to injections every 4 or 8 weeks or no injections at all compared to continual dosing every 2 weeks, which is the recommended therapeutic regimen.^{10,11} A total of 72% of patients who maintained weekly or every 2 week doses stayed with well controlled symptoms. However, only 58% of patients who reduced the frequency to every 4 weeks, 55% of patients who reduced the frequency to 8 weeks or 30% of patients who withdrew from dupilumab remained well controlled.¹⁰ Under the conditions in these studies, it was not recommended to reduce or withdraw from dupilumab to maintain optimal clinical response.^{10,11}

Instead of trying to stop taking dupilumab, several studies have focused on tapering the dose once the disease is well controlled for a significant period of time. The approved treatment regimen for adults is 600mg dupilumab at first followed by 300mg every 2 weeks. The dosage and frequency for pediatric patients varies based on age and weight.

In a 2023 study, researchers had 29 adult patients who had well-controlled AD symptoms for 8 months go from 300mg dupilumab every 2 weeks to 300mg every 3 to 4 weeks. AD symptoms stayed well controlled in 83% of patients on this treatment schedule indicating that patients may not need to be treated as often for dupilumab to stay effective.¹²

Two additional studies have looked at reducing the interval between dosing of dupilumab to every 3 or 4 weeks and to every 6 to 8 weeks after having achieved well-controlled AD for 6 months.^{13,14} In both cases the disease severity scores did not worsen in over 80% of patients who were treated less often, although some increased itch was reported when dose frequency was reduced to every 3 to 4 weeks.^{13,14} Since the majority of AD patients indicate that reduction in itch is of highest priority, even a small increase in itch may cause them to stay on the more frequent dose of dupilumab.¹

Oral JAK inhibitors

There are very few studies to date about reducing or stopping treatment with oral JAK inhibitors (JAKi). These medications have not been approved for eczema treatment for very long or are still in clinical trials. Dr. Shi emphasized that it is important to match disease history with proper treatment in order to have the best chance of deciding if you need to stay on medications year-round or can go on and off medications seasonally. “If your disease activity is constantly high all year, you would benefit most from being on JAKi therapy all the time,” explained Dr. Shi.

“If your disease activity is seasonal or cyclic, you may be able to control your symptoms with JAKi therapy only during higher states of disease activity,” Dr. Shi said. “JAKis are available in two doses, and usually doctors use the lowest dose that controls your symptoms. This gives the option to increase or decrease the drug dose as needed for control. You should never just go on and off medicines without instructions from your doctor.”

“JAKis are available in two doses, and usually doctors use the lowest dose that controls your symptoms. This gives the option to increase or decrease the drug dose as needed for control.” ~ Dr. Shi

One study was recently published on reducing doses of baricitinib, a JAKi that has demonstrated long-term efficacy at treating AD over a full year in clinical trials but has not yet been FDA approved for AD treatment. Patients who had completed the long-term clinical trial on 4mg baricitinib for 52 weeks and were well controlled were re-randomized to stay on the 4mg dose or to taper to 2mg or 0mg (placebo) of the drug.¹⁵ While 87% of patients who continued to be on the 4mg dose that they had been on for the 52 weeks remained clear, almost clear or with mild skin symptoms, 61% of patients taking 2mg baricitinib and only 50% of patients who were removed from the drug remained clear, almost clear or with mild skin symptoms.¹⁵ For those who had originally been on 2mg baricitinib, 92% that stayed on 2mg experienced clear, almost clear or mild symptoms, while 71% who took 1mg and 45% who were removed from the drug remained clear, almost clear or with mild symptoms. Thus, it is possible to taper the drug to a lower dose in about two-thirds of cases, while only half or fewer patients who discontinued the drug remained with controlled disease.

In this study, it was also determined that 80–88% of patients who returned to the 4mg dose after tapering or going off the drug were able to effectively recontrol symptoms.¹⁵ Staying on the 2mg dose was better than the 1mg dose going back to 2mg, (90% to 56%, respectively), while 86% of those who had been off the drug and reintroduced 2mg returned to clear, almost clear or mild symptoms.

Studies on tapering or discontinuing other JAKis that have been FDA approved, abrocitinib¹⁶ and upadacitinib,¹⁷ have also been completed. For abrocitinib, 80% of patients removed from the drug experienced worsening of symptoms, but 82% of those patients returned to controlled disease after being reintroduced to 200mg abrocitinib.¹⁶ For upadacitinib, patients who were removed from the drug rapidly showed worsening of symptoms but improved rapidly when given 30mg upadacitinib. This was a very small study with each group only having between 10 and 20 patients.

Overall, tapering JAKis may be feasible, but most studies are still not recommending going off the drug. However, knowing that you can start again on the drug and the disease will respond again is reassuring.

Finally, Dr. Shi offered the following advice about staying on or going off treatment with JAKis: “For many people, AD can be a lifelong condition that may require long-term therapy. The discussion of discontinuation of a JAKi due to improvement of condition comes down to informed decision-making between you and your provider. You could try a drug holiday in close observation by your healthcare provider to determine how your disease responds. Your provider should be able to tell you the risks and benefits of tapering a drug or a drug holiday. As a dermatologist, I will make my ultimate recommendation after considering my patients’ unique AD history and goals.”



Talk to your doctor before stopping any medications

There is still more research that needs to be done on stopping certain AD medications, taking a temporary drug holiday or reducing drug dosage. Some of the medications and treatments are so new there is no substantial real-world data yet. Healthcare providers do have some best practices and emerging data to help inform their recommendations and discussions with patients.

Here is Dr. Lio’s approach when patients with AD ask to reduce or stop a medication: “We have a goal of being clear from disease or nearly so, and symptom-free for at least a few months before we try to reduce or discontinue medications. Otherwise, we are simply

undertreating which can be a lose-lose for everyone. Once disease control is achieved, we may be able to carefully taper and see how the skin responds. Skin is a dynamic organ and eczema is a very dynamic disease, so the only way to really know is to try.”

In the end, the most important thing to remember is that you should never stop your AD medications without consulting with your healthcare providers about the best way to do so. One of the reasons you may be doing so much better with your AD symptoms is because of the medicine you’re taking. A good strategy is to continually talk with your doctor about your treatment goals and share any issues or concerns you’re facing.

In the end, the most important thing to remember is that you should never stop your AD medications without consulting with your healthcare providers about the best way to do so.

Key takeaways:

- AD is chronic and may need to be treated with medication for life.
- There has not yet been much research on maintaining or regaining disease control after stopping or minimizing treatments for AD. There is always a risk of symptoms relapsing with reduced treatment or no treatment.
- There are different types of treatment options for AD ranging from topical to systemic. Each treatment has different considerations for staying on the drug long-term or reducing its frequency of use.
- Patients should always talk to their provider prior to reducing or stopping AD medication(s).

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GET THE FACTS

Snail Mucin and Eczema

By Celia Shatzman

Snail mucin might seem like a trendy new ingredient, but its history actually goes way back — we're talking ancient Greece. In that long ago era, snail mucin was used for its anti-inflammatory properties to prevent or treat skin infections, and as an anti-aging agent, according to Dr. Paul Yamauchi, dermatologist at the Dermatology Institute and Skin Care Center in Santa Monica, California and affiliated with UCLA School of Medicine.

"Recently, snail mucin has been formulated in several skincare products by various companies and the value is approaching \$770 million dollars in 2025," Dr. Yamauchi said. "There is limited research on snail mucin although the commercial development has gained huge popularity based on consumer perspectives and successful marketing strategies."

What is snail mucin?

Snail mucin refers to the slimy secretion that is produced naturally by snails. "Containing hyaluronic acid, it serves as a humectant to draw moisture in and also contains zinc and allantoin to help soothe the skin and calm inflammation," said Dr. Marisa Garshick, a board-certified dermatologist at MDCS Dermatology: Medical Dermatology and Cosmetic Surgery in New York City and New Jersey. "Snail mucin is thought to help moisturize the skin and help boost hydration. It has been commonly incorporated into K-beauty [Korean beauty] products, now being increasingly recognized for its ability to help nourish the skin."

Dr. Yamauchi adds that snail mucin are large protein molecules that are coated sugar molecules that have several functions such as adhesion, lubrication, hydration and antimicrobial effects. These properties allow a snail to stick to any surface and allow for antimicrobial defense.

Why is snail mucin trending in skincare now?

"Snail mucin is rich in several compounds which can be beneficial to skin," said Dr. Rebecca Marcus, a board-certified dermatologist at North Dallas Dermatology Associates in Dallas, Texas. "Snail mucin has been noted for its ability to hydrate skin and promote wound healing. In addition, it may have anti-aging properties as it is made up of compounds including peptides and antioxidants that promote collagen synthesis and elasticity. Snail mucin is also known for its anti-inflammatory and soothing properties, which may help to calm irritated or compromised skin."

What is the science behind snail mucin?

The skin barrier is disrupted in eczema, allowing for inflammation, dryness and itching to occur. "Because of its hydrating and lubricating properties, snail mucin can provide moisturization to the skin and provide soothing relief," said Dr. Yamauchi. "People with eczema are more prone to skin infections as a result of scratching which allows bacteria to enter into the skin. Because snail mucin has been shown to exert antimicrobial properties, applying it could treat and prevent skin infections."

Though more research is needed to fully determine the benefits in the setting of eczema, one study showed that it may offer an anti-inflammatory benefit.¹ "As a humectant, it works well when layered with moisturizing creams that contain ceramides to help support and strengthen the skin barrier, as this can help to lock moisture in," Dr. Garshick said.

Is snail mucin a safe ingredient for people with eczema?

As long as a person does not exhibit an allergic reaction and it is tolerable (no stinging or irritation), a skincare product that contains snail mucin should be safe for people with eczema regardless of severity, according to Dr. Yamauchi.

However, it's important to consider what else is in a skincare product's formula besides snail mucin. "For example, many formulas include fragrance to mask snail mucin's characteristically strong smell," cautioned Dr. Marcus. "Fragrance is a notoriously irritating ingredient that should be avoided by those with atopic dermatitis. Therefore, if a product containing snail mucin also contains fragrance, or any other potentially irritating ingredient, it would be best to avoid this product."

Those with eczema should be cautious when using any new product, so Dr. Garshick always recommends doing a patch test with any new product prior to use. "This can be done by testing the product on a small area on the inner elbow or wrist to see how the skin reacts," she advised. "Prior to incorporating snail mucin into a skincare routine, it is important to check with your board-certified dermatologist to determine if it is best for you."

¹ Ricci A, Gallorini M, Feghali N, Sampò S, Cataldi A, Zara S. Snail Slime Extracted by a Cruelty Free Method Preserves Viability and Controls Inflammation Occurrence: A Focus on Fibroblasts. *Molecules*. 2023; 28(3):1222. <https://doi.org/10.3390/molecules28031222>

LIFESTYLE

How to Spring Clean Your Home and Reduce Flares

By Melissa Tanoko

Spring is a welcome return to longer, brighter days. But it can also shine a light on dust and dirt. This could be why 74% of Americans clean their homes every spring.¹

For people with eczema, though, spring cleaning isn't that simple. It can help prevent flares caused by indoor allergens, irritants and bacteria. But since the act of cleaning can also cause flares, many may decide not to bother.

We reached out to Dr. Ari Zelig, an allergist and immunologist with Charleston ENT and Allergy in Charleston, South Carolina, and Morgan Maier, a dermatology physician assistant at Seattle Children's Hospital in Seattle, Washington, to find out how to prevent flares while making the most of your spring cleaning.

Why spring cleaning matters when you have eczema

Home is a cozy space to unwind, but it also houses a few major allergens that can trigger eczema. "When it comes to indoor allergens, we most commonly refer to dust mites, pets, mold and cockroaches," said Dr. Zelig.

Although these allergens are usually associated with respiratory symptoms, dust mites, pet dander, mold and cockroaches can cause eczema flares.² Minimizing or preventing them at home can help avoid future flares.



What to wear

If you have eczema, protecting your skin from dirt, allergens, chemicals, water and sweat while cleaning is vital.

“If you are stirring up dust and animal dander while cleaning, it is wise to wear clothes that cover up your active skin lesions,” said Dr. Zelig. “This measure, together with the use of gloves, can prevent chemicals and allergens from coming in contact with your skin, which can lead to further inflammation and eczema flares.”

People with eczema “should try to wear long sleeves that are lightweight so that they have protection from external allergens touching their skin, like dust mites or irritants from cleaning products,” said Maier.

People with eczema “should try to wear long sleeves that are lightweight so that they have protection from external allergens touching their skin, like dust mites, or irritants from cleaning products.”

~ Morgan Maier

She also recommends breathable fabrics made of cotton or Tencel (made of lyocell and modal fibers) to prevent irritation from working up a sweat.

Wearing gloves is also advisable, especially if you have hand eczema. Maier recommends using cotton gloves for dry work like dusting. If the tips of your fingers don’t usually flare, you may cut the fingertips off the gloves for extra dexterity.

For washing bathrooms or mopping floors, waterproof gloves are essential. They help guard hands against the skin barrier breakdown that can occur when skin is wetted and dried repeatedly. They also protect the skin from cleaning chemicals.

However, rubber gloves should be avoided as the latex can cause allergies. Opt for unlined vinyl or neoprene ones instead. Maier recommends wearing a pair of cotton gloves inside loose-fitting waterproof ones. She explained that this helps reduce chafing. Be sure to give your hands a break every 15-20 minutes to prevent them from getting too sweaty.

Eczema-friendly cleaning tools

The right tools can help you get the job done quickly and thoroughly without irritating your skin.

When possible, use cleaning tools with long handles instead of scrubbing with rags to give your hands a break. Maier recommends microfiber mops. “You can use them dry to dust your walls,” she said. “You can use them wet to wash the tile in your bathroom, so you’re not using a sponge. And it gives you more distance from the products.”

Microfiber cloths are often recommended as a great way to disinfect surfaces using only water. While some research has found they can help reduce bacteria,³ other studies show that cotton cloths are more effective than microfiber after multiple washes.⁴

Eczema-friendly cleaning products

Many cleaning agents have fragrances or harsh chemicals that can trigger flares. But knowing which ingredients to avoid can be a challenge.

“I would recommend having patch testing performed with your allergist or dermatologist in order to identify your contact allergens,” said Dr. Zelig. “This will allow you to screen ingredient lists and to generate shopping lists for products that are free of your allergens.”

Maier recommends homemade cleaning products. She explained that a 50/50 water and vinegar mix can be used to clean and disinfect, while baking soda is good for scrubbing.

What to clean

Spring cleaning tasks can quickly multiply. Set limits on your to-do list by targeting the areas where indoor allergens are most likely to be found.

Windows

Washing windows in spring helps decrease dust and mold while improving your view of the new leaves outside.

Dust window frames and blinds, then wash the windows, inside and out. If you notice mold on the windows or frames, be sure to remove it. Also, check for any openings or cracks in the frames, which can allow mold to thrive.

“When washing windows, wash your screens too,” said Maier. “I take all mine out to my yard. I line them up against the deck and spray them with a hose.”

Bedroom

Since people typically spend six to 12 hours in the bedroom each night, minimizing allergens here is especially important.

“Dust mite covers for the bedding are helpful,” said Dr. Zelig. These can trap the mites inside and minimize their allergenic potential. If you invest in dust mite covers, look for products made with breathable fabrics.

If you have children, cleaning their stuffed toys is another priority. Some research has shown that washing plush toys in hot water or putting them in the freezer overnight reduces dust mite populations.⁵

Living Room

With its many books, electronics, knick-knacks and fabrics, the living room is a magnet for dust and pet hair. Give the whole area a good dusting.

Maier stressed the importance of pulling larger furniture pieces like sofas away from the wall and vacuuming the dust and dirt collected underneath.

Area rugs and carpets can also store large quantities of dust. Vacuum them thoroughly. If you live in a humid climate, consider steam cleaning them to reduce dust mites.⁶ Fabric furniture and heavy drapes should be vacuumed and steam cleaned, if possible.

Bathrooms

Reducing mold is the top priority here. Wash any windows and check the frames for mold. Then, wash or replace your shower curtains and liners. Empty out bathroom cabinets and clean them thoroughly. Look for signs of mold that may indicate a leak. Check for openings around bathroom pipes that can allow pests like cockroaches to enter your home.

Kitchen

Deep cleaning your kitchen can help prevent cockroach invasions and mold growth. Pull the fridge and range away from the wall to clear away any dust or food particles. Empty the cupboards and clean them thoroughly. Under your sink, check for openings or signs of mold.

Clear the air

With pollen season on the way, spring is the perfect time to clean air conditioners and purifiers. Maier also recommends taking fans apart and wiping them down.

“Replace the filters on vacuums, air filters and furnaces, making sure that all the filters have been replaced within a reasonable amount of time,” said Maier.

Keep up the good work

Maier and Dr. Zelig agree that keeping on top of cleaning is beneficial for people with eczema, especially for those with allergies to dust mites, pet dander, mold or cockroaches.

“The more regularly you continue to take environmental precautions, the more effective the measures will be,” said Dr. Zelig. He recommends “very regular dusting, vacuuming and washing sheets in hot water once weekly.” Maier advises vacuuming fabric surfaces like sofas and curtains monthly.

In addition to reducing the risk of flares, keeping up a recurring cleaning schedule has another benefit — you’ll have less work to do next spring!

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MY JOURNEY

Dealing with Step Therapy

By Erin Laviola

Edward Taguba, 46, has finally found relief from his severe atopic dermatitis. "I don't feel shame anymore, and I feel at peace because I don't itch as much as before," he said.

It's been a lifelong struggle to get here. Taguba, who lives in Oahu, Hawaii, cycled through countless medications over the years because of step therapy. Under the protocol, insurers may deny coverage for doctor-prescribed medications until the patient tries and fails one or more lower-cost alternatives first.

Despite all he's been through, Taguba's battle isn't over yet. The solution that has, at long last, calmed Taguba's eczema may be only temporary because of an insurance denial.

A childhood mystery

When Taguba was 8, he developed what he thought was an itchy rash on his arms and neck. As he got older, it spread to his face and scalp.

Taguba recalls regularly scratching to the point of bleeding. "I wore long sleeves to cover it up but then I'd have red spots on my clothes from the blood," he said. "It was embarrassing."

Photo by Felix Fernandez Photography

It was a mystery for most of his childhood. He grew up on the small Hawaiian island of Lana'i, which he said had only one general doctor. Taguba's parents flew him to visit specialists in Honolulu, but no one could identify his symptoms.

After graduating from high school, Taguba finally received an answer from a dermatologist in Oahu who diagnosed him with severe atopic dermatitis. She told him there was no cure, but medications could help control it.

Trying it all

The diagnosis kickstarted a decades-long search for the best treatment. Taguba said he tried every ointment, cream, pill or injection his dermatologist could prescribe.

"Going through step therapy is like trial and error," he explained. "We'd get my eczema under control for a while, but after a few months it would flare up again and we'd have to try something else."

Taguba said steroid shots offered some relief, but only briefly because they can be administered only every few months. In between injections, his symptoms would worsen to the point where he couldn't help but scratch. "My face would be raw and my eyelids were swollen from rubbing my face."

Taguba's eczema also often left him with open cuts when it spread across his body. His breaking point came in 2017 when an open wound on his foot became infected from a visit to the beach. "The infection spread and I was in the hospital for nearly two months."

Turning to biologics

Taguba said the life-threatening experience prompted him to "wake up" in a sense. After nearly 20 years of taking steroids, which had failed to prevent his infection, he was adamant about trying something new.

"I told my doctor I didn't want steroids anymore," explained Taguba.

The timing was in his favor. The FDA had recently approved Dupixent, a new biologic treatment for eczema that requires patients to self-administer an injection every 14 days. Taguba said his eczema calmed significantly after using Dupixent for a few months.

Adding the nonsteroid cream

Although Taguba responded well to the biologic, his severe atopic dermatitis was still prone to outbreaks between injections.

In 2022, his dermatologist prescribed a nonsteroid cream in addition to the Dupixent. When Taguba begins to feel itchy, he applies the cream and it prevents a flare.

He said the combination of the two medications has granted him a freedom he'd never felt before. "There's normalcy in my life now."

An insurance roadblock

Unfortunately, Taguba's hard-earned relief could be short-lived. His medical insurance has denied authorization for the cream.

Taguba said his medical insurance denied the cream because he is on Dupixent. They told him "because you're already on another drug, Dupixent, we cannot approve the cream too," he said.

He is currently appealing this medication denial with his insurance company. In the interim, his dermatologist is supplying samples of the cream to help him as best as they can. But this is not a long-term plan.

After struggling his entire life to find a remedy for his eczema, Taguba is bewildered that the insurance company would refuse to pay for a solution that finally worked.

"It's important to let doctors prescribe what will actually help their patients," Taguba said.

"It's just like how diabetes patients depend on insulin. It's the same thing with eczema," Taguba said. "We depend on these drugs to help us live our lives."



Fighting step therapy

To help put an end to step therapy for eczema patients, NEA is advocating for the Safe Step Act in Congress. The **Safe Step Act** (H.R. 2630/S. 652) would ensure that patients can seek an exception if their health plan delays covering medically necessary treatment by requiring the patient to try and fail on a different medication first.



You can help push for the Safe Step Act by reaching out to your legislator and asking that they cosponsor the legislation. Scan the QR code to contact your legislator in two clicks.

Meeting Other Kids with Eczema Changed Her Son's Outlook on Life

By Jennifer Moncayo-Hida



Photos courtesy of Lindsay Taylor

Eczema can leave you feeling isolated and alone. And this can be especially true for kids with eczema. Lindsay Taylor, from Adel, Iowa, watched her oldest son, Camber, 9, struggle with eczema for years and saw the way it negatively affected his mental health. Below she shares a little of Camber's eczema journey and how she saw him transform from shy and short-tempered into a confident, optimistic kid after he met other young people with eczema.

NEA: When was your child, Camber, diagnosed with eczema?

Lindsay Taylor: Camber was 1 1/2 years old when he was diagnosed with atopic dermatitis. It started with a little spot on his face and his knees — kind of no big deal. His pediatrician gave him topical steroids to start, but it kept getting worse.

We received all sorts of diagnoses, everything from chicken pox to hand-foot-and-mouth disease. By the time he was 3 years old, he could not sleep alone. He would itch at naptime and in the night so badly that he would bleed.

NEA: What hurdles did you encounter in the beginning of Camber's diagnosis?

LT: At the beginning it was mainly just physical. What doctor can I see that can give me an answer? What do I put on his rash? How do I get

him to sleep? How do we keep him comfortable at night? It was a lot of figuring out what was causing it. At one point, we thought he was allergic to the dog, so we got rid of our dog. We were willing to do anything to help him.

The doctors we were seeing were not helping us. We spent a lot of time in that stage. I didn't know what health professionals I could trust or how to move forward to help my son. That's how I felt for a long time.

And then it became the mental aspect of it: how are we going to manage this for our family?

NEA: What are some of the ways that eczema affected Camber?

LT: When he was young it was just something that hurt him, and mommy had to put lotion on him. As he got older, it started to affect his behavior.

Camber was a good kid. He was a rule-follower by nature. He was shy and quiet at school and his teachers loved him. But his eczema made doing certain things hard.

We described Camber as our "glass half-empty kid." He could be upset at Disney World. His perspective was everything sucks. He did not enjoy things. He was short-tempered. We could see glimpses of him, but eczema really affected who he was.



Camber during TSW

When he was 7 years old, he went through topical steroid withdrawal (TSW) and his eczema became something that made him feel so different from others. He would say, "I don't belong in this family. You're normal and I'm not."

That year was tough. We reassured him that we loved him and would always love him no matter what. As a 7-year-old, he didn't have the perspective to see the other side of TSW. He just knew he didn't want to live like that.

During TSW, he didn't really play outside because the wind and weather would hurt his skin. He just felt like he couldn't even be a kid. During a flare, he was often bed and couch bound. He would go to school if he was not going through a flare, but he was not going to recess or gym class.

Camber felt so alone during the worst of it. He didn't think there was another person like him. I tried showing him stories of others in Facebook groups, but it didn't matter.

NEA: How has Camber's relationship with eczema evolved over the years?

LT: Things changed after we went to Eczema Expo 2022 in Seattle. One of Camber's doctors, Dr. Olivia Friedman, told us about it, and we applied for a scholarship to attend Expo. We were camping when we found out we got a scholarship. Camber literally danced in the rain because he was so happy. He said, "I get to meet other kids like me!" His perspective changed before we even got to Expo. He was more optimistic about things.

At Expo, Camber met Matt, a 17-year-old who had sort of been in Camber's shoes at that age. He felt like he had people who understood his pain and struggles.



Matt and Camber

When we got home, he talked a lot about being a "Matt" someday for other kids at Expo Camp. He started saying things like: "I'm going to be able to help kids with eczema."

Now we talk about life before and after Expo. Camber was a totally different person after Expo. It was life-changing for all of us. It's hard to think back about some of these things. It's funny now to think we ever described Camber as a glass half-empty kid. He has such a different perspective now.

NEA: How has Camber changed after meeting other people with eczema?

LT: His confidence has grown exponentially! Last year, his counselor asked him if he wanted to talk to the class about his eczema and he was against it. He is kind of a shy kid. This year, he went to a new school, and he decided to talk to his class about his eczema. He told them that he's not contagious and answered his classmates' questions about it. It was super empowering for him to talk to his classmates. He's gained so much confidence in the last year.

He also has such a mature outlook on life now. He wants to go into a career where he can help others with eczema.



CAMBER IS THIS YEAR'S

ITCHING FOR A CURE HERO!

Join Camber and the Taylor family in fundraising for Itching for a Cure. All funds help support eczema research. Learn more and set up your fundraiser at ItchingForACure.org.



5 Common Places Dust Mites are Lurking

By Melissa Tanoko

Allergies to microscopic creatures living in dust, also known as dust mites, are very common.¹ Roughly 20 million people in the U.S. have a dust mite allergy.²

Since allergies often go hand-in-hand with eczema, dust mites can be an issue for many in this community.³

“When dust mite allergens penetrate the skin barrier of patients with eczema, it can lead to allergic and inflammatory responses in the skin that cause further redness, scaling and itching,” said Dr. Ari Zelig, an allergist and immunologist with Charleston ENT and Allergy in Charleston, South Carolina.

“When dust mite allergens penetrate the skin barrier of patients with eczema, it can lead to allergic and inflammatory responses in the skin that cause further redness, scaling and itching.”

~ Dr. Zelig

According to Dr. Zelig, other symptoms can include itchy eyes, a stuffy nose and sneezing.

Dr. Zelig explained that dust mites can also exacerbate asthma symptoms. “For those with asthma triggered by dust mites, it may lead to cough, shortness of breath, chest tightness and wheezing,” he said.

This is why taking steps to minimize dust mite exposure is often recommended for people with eczema. Knowing where dust mites live is key to keeping them — and the symptoms they can cause — in check.



1. Areas with high humidity

Dust mites require humidity to survive. Dr. Michael Nevid, a pediatric allergist and immunologist at National Jewish Health in Denver, Colorado, explained that dust mites “don’t drink water; they actually absorb moisture from ambient air.”

As a result, they can’t live when indoor relative humidity levels are consistently below 50%.⁴ If you live in a drier climate, dust mites likely won’t be an issue for you.

For people living in more humid climates, dehumidifiers can be an important first intervention. Some research found that even when indoor relative humidity levels rose above 50% for two to eight hours each day, dust mite populations were still controlled, as long as humidity levels stayed below 50% the rest of the time.⁴



2. Beds

Beds are a favorite dust mite hangout. There is ample soft fabric to hide in and easy access to dust mites’ primary food source — dead skin cells.

Tightly woven dust mite covers that encase pillowcases and mattresses, trapping dust mites inside, are sometimes recommended. However, Dr. Nevid cautioned that dust mite covers are only part of the solution.

“Even though they might decrease the amount of dust mites, or the allergenic material that’s found outside of those coverings, that on its own often may not be enough,” he said.

Dr. Nevid recommends washing bedding such as pillowcases, sheets, blankets and duvet covers in hot water weekly. A temperature of 130-140 degrees Fahrenheit is ideal.² Putting the laundry through a hot dryer also kills dust mites.⁵

If you do invest in dust mite covers, look for products made of breathable fabrics. Plastic materials on mattresses or pillows may cause sweating, which can irritate the skin or cause flares.

Soft, stuffed toys, often an essential fixture on children’s beds, are also known to harbor dust mites. One study found that putting them in the dryer for an hour, freezing them overnight or washing them in water mixed with eucalyptus oil were effective ways to reduce dust mite numbers.⁶

Purifying the air with a high-efficiency particulate air (HEPA) filter is another recommended strategy to diminish dust mite allergens in the bedroom.²



3. Carpets

With their many soft fibers and crannies for dust to settle in, carpets are another popular dust mite habitat.

Dr. Nevid recommends removing carpets, if possible, especially in bedrooms. He also advises people with dust mite allergies to clean carpets regularly with a HEPA filter vacuum.

Some research also found that steam cleaning carpets effectively reduced dust mite populations.⁷



4. Fabric furniture

Dr. Nevid explained that upholstered furniture can be another common dust mite breeding ground. These can be a little trickier to deal with since the cushion covers can’t typically be washed as often using high heat.

Leather or vinyl furniture is considered to be preferable to fabric for dust mite control,⁸ but these may increase sweating, which is not ideal for people with eczema. Opting for furniture with easily washable covers may be helpful.

Steam cleaning has the potential to reduce dust mites in fabric furniture. However, not all upholstered furniture can withstand steam cleaning. Check the labels on your furniture or the manufacturer’s website before trying it.



5. Basements

According to Dr. Nevid, areas with poor ventilation that tend towards dampness, like basements or the first floor of a building, can also have high dust mite numbers.

Reducing humidity in these areas, either by using a dehumidifier or opening windows periodically, could be helpful. Be sure to follow other recommendations like removing carpeting or minimizing upholstered furniture here.

Also avoid bedrooms in a basement or on the first floor if you have a dust mite allergy. Bedrooms located on the second floor or above are more ideal.⁵

Seek medical advice

Although doing what you can to minimize dust mites at home can help manage eczema flares or other dust mite allergy symptoms, it’s also important to seek personalized advice from medical professionals.

Allergists can not only diagnose dust mite allergies but also help treat them. Immunotherapy is often recommended for dust mite allergy.

“Allergen immunotherapy, which most people might know as allergy shots, is typically given as injections, although there are sublingual options for dust mite allergy under the tongue,” said Dr. Nevid.

According to Dr. Nevid, immunotherapy “has been shown to be effective for dust mite allergy and patients who have eczema.”

Talking to an allergist is a great way to get personalized advice and treatment for your unique circumstances.

1. Dust allergies. Acaai.org. Updated February 2, 2018. Accessed January 5, 2024. <https://acaai.org/allergies/allergic-conditions/dust-allergies>. 2. Aggarwal P, Senthilkumaran S. Dust mite allergy. *StatPearls*. 2023. <https://www.ncbi.nlm.nih.gov/books/NBK560718/>. Accessed January 5, 2024. 3. Nankervis H, Pynn EV, Boyle RJ, et al. House dust mite reduction and avoidance measures for treating eczema. *Cochrane Database Syst Rev*. 2015;19(1):CD008426. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8407038>. 4. Arlian LG, Neal JS, Vyszenski-Moher DL. Reducing relative humidity to control the house dust mite *Dermatophagoides farinae*. *J Allergy Clin Immunol*. 1999;104(4):852-856. [https://www.jacionline.org/article/S0091-6749\(99\)70298-8/fulltext](https://www.jacionline.org/article/S0091-6749(99)70298-8/fulltext). 5. Wilson JM, Platts-Mills TAE. Home environmental interventions for house dust mite. *J Allergy Clin Immunol Pract*. 2018;6(1):1-7. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6474366>. 6. Chang C-F, Wu FF-S, Chen C-Y, Crane J, Siebers R. Effect of freezing, hot tumble drying and washing with eucalyptus oil on house dust mites in soft toys. *Pediatric Allergy Immunology*. 2011; 22: 638-641. <https://onlinelibrary.wiley.com/doi/10.1111/j.1399-3038.2011.01144.x>. 7. Colloff MJ, Taylor C, Merrett TG. The use of domestic steam cleaning for the control of house dust mites. *Clin Exp Allergy*. 1995;25(11):1061-1066. <https://pubmed.ncbi.nlm.nih.gov/8581838>. 8. Cinteza M, Daian C. House dust mite - the paradox. *Maedica*. 2014;9(4):313-315. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4316872>.



RELATIONSHIPS

How to Manage Intimacy and Physical Touch With Your Partner When Your Eczema is Flaring

By Meghan Gallagher

Physical touch with a partner can pose a challenge when your skin flares. And whether you're with a new or a long-term partner, navigating conversations about intimacy and eczema can feel like a mental rollercoaster.

We spoke with Summer Forlenza, a licensed therapist at Forlenza Marriage and Family Therapy, Inc. and a person with eczema, as well as Patricia Cervini, an outspoken eczema advocate, about managing physical touch during a flare. Each provided deep insights into physical intimacy with eczema and normalized the mixed emotions that often accompany exposing flaring skin.

How to talk about eczema with your partner

Eczema can feel isolating in the bedroom, but you're far from alone. One study found up to 57% of adults with eczema experience difficulty with intimacy or try to hide their skin from intimate partners.¹

"When physical intimacy is involved, it's in everyone's best interest for you to be open, honest and communicative about your skin and needs," recommended Forlenza, who specializes in treating trauma and abuse in her practice in Rancho Cucamonga, California. If you're seeing a new partner, she advises choosing a private, comfortable setting to talk about your eczema.

You can ask if they've noticed your rashes, explain what eczema is if they're unfamiliar and answer any questions. "I think it also

points to the other person's character," said Cervini, 59, who lives in Washington, D.C. "If that's going to scare them away, do you want to be with someone like that?"

Long-term relationships offer opportunities to build deeper connections and boost your self-confidence. "Your partner can be a safe person who understands that eczema is more than 'just a rash' and that it impacts your identity and daily life," said Forlenza. "Maybe they can help you to see yourself and your skin in a different light over time."

Cervini met her husband about eight years before her eczema became more severe. "When it began to get really bad, starting with my calves, Henry saw the struggle, but never did he indicate it was a problem," Cervini said. "What was most helpful was that he knew that it wasn't contagious. He's never made me feel unattractive, undesirable or anything negative."

How to manage physical touch during an eczema flare

Eczema may add a layer of complexity to intimacy, but enjoying intimate moments with a partner is very possible. It's all about thinking ahead, getting creative and prioritizing your needs and comfort. Here are a few tactics to help you and your partner with physical touch.

1. Maintain open, honest communication.

As in any relationship, it's vital to communicate your needs. You are the expert on your skin. "If parts of your body are in pain, let them know," said Forlenza. "This can be as simple as saying, 'I'm flaring on my inner thighs today, so please be gentle with me there.'"

And vice versa, let your partner know what feels good to help them support you. Regular, healthy communication can bring you closer to your partner and deepen your connection over time.

2. Minimize your triggers.

Does heat exacerbate your flares? Forlenza recommended setting up fans before sex or physical intimacy or making sure to run the air conditioner. If you're particularly sensitive to fragrance, try to use cotton bedding and avoid contact with clothes washed in fragranced detergents.

Sweat can also trigger a flare for many people with eczema, so take breaks to cool down as often as needed. "Sex should be fun and feel good, and if your skin starts to interrupt that, it's OK to take a step back and focus on whatever does feel good," said Forlenza. You can also take breaks to grab an ice pack from the freezer or invite your partner for an intimate cool-down shower.

3. Explore new ways to deepen intimacy.

Sometimes flares can become too itchy and painful for sex or certain physical activities. "Any healthy sexual relationship will not only accept but celebrate your 'no' because it honors your needs and

maintains a healthy sense of trust in your intimate relationship," assured Forlenza.

When this happens, take time to explore different ways to deepen your relationship. You can prioritize cuddling, kissing and hand-holding instead. Or, if your eczema flares around your hands or mouth, perhaps your partner can help you apply lotion to your sensitive areas. You could also talk through a list of questions designed to deepen romantic connections as a non-physical option.

4. Work on your self-confidence and body image.

Revealing your flaring skin to a new or long-term partner can feel vulnerable. Eczema can impact your confidence and body image, and many people will often find ways to avoid the topic entirely. However, the more you practice being open about eczema with a partner, the more your confidence can grow.

Eczema can impact your confidence and body image, and many people will often find ways to avoid the topic entirely. However, the more you practice being open about eczema with a partner, the more your confidence can grow.

"My advice is to start slow and give yourself permission to accommodate yourself if it helps," said Forlenza. "Low lighting or cozy pajama tops are OK if they help you to be more open to intimacy."

When you become comfortable talking about your eczema, you encourage your partner to feel the same. "I also think at some point you have to have a sense of humor about it," noted Cervini. "And your partner will likely take the cue from you." A sense of humor can help break down walls and lay the foundation for more transparent communication between you and your partner.

Feeling safe in intimate moments

Dealing with an eczema flare can be frustrating and challenging. Being open with your partner about how you're feeling and your comfort level for intimacy and physical touch when you're going through a flare is key to having a healthy relationship. "Having experiences of intimacy where you allow yourself to be vulnerable in a safe environment can be healing and empowering," Forlenza said.

¹. Ring, J., Zink, A., Arents, et al. Atopic eczema: burden of disease and individual suffering – results from a large EU study in adults. *J Eur Acad Dermatol Venereol*. 2019; 33: 1331-1340. doi. org/10.1111/jdv.15634

How to Take Care of Your Lips When You Have Eczema

By Jamie Wilson



Look for the Seal

New in 2024, NEA has added lip care to the Seal of Acceptance™ product categories with awarded products expected later this year. In the meantime, find eczema-friendly moisturizers and other over-the-counter products at [EczemaProducts.org](https://www.eczemaproducts.org).

Eczema flares can occur anywhere, but experiencing a flare on or around the lips can not only be highly uncomfortable but trickier to treat than other areas — much like the treatment of eczema on the eyelids. While a flare on the arms or legs can be wrapped or covered by appropriate clothing to cause less irritation, that doesn't always apply to a flare up that's occurring right in the middle of your face.

"Eczema of the lips most often occurs as redness, scaliness, tenderness, itchiness and/or swelling," said Dr. Blair Murphy Rose, a dermatologist and clinical instructor of dermatology at the Weill Cornell Medical Center in New York City. Any of these symptoms can make something as simple as washing your face, brushing your teeth, and even eating certain foods difficult, especially when managing swelling and tenderness. Ahead, we'll look at how to prevent and treat eczema flares on the lips.

How to prevent eczema flares on the lips

When it comes to trying to prevent an eczema flare, it's best to start with identifying possible triggers. Dr. Rose notes that irritants are a huge cause. In flares around the lips, these irritants are often present in products like lipsticks, lip balms, foods and even saliva from licking your own lips can all potentially cause or worsen a flare.

While you might not be able to completely stop a habit like licking your lips, anyone managing eczema can avoid common allergens and skin irritants like fragrance, menthol, camphor, dyes and parabens.

One of the best ways to "prevent eczema flares on the lips is by keeping lips moist with an occlusive topical," said Dr. Rose. This is where essential products like hypoallergenic, petroleum-based moisturizers come to good use.



How to care for and treat eczema flares on or around the lips

There are various types of eczema, which may each present differently on the face. For example, seborrheic dermatitis often presents itself as flaky or oily patches of skin, whereas atopic dermatitis usually presents as dry, itchy skin. However, although 88% of adults with seborrheic dermatitis will experience flares on their face, lesions are most commonly seen on the forehead, eyebrows or around the nose with this type of eczema — not on the lips.¹

So, while each type of eczema might cause different issues when it comes to flares, Dr. Rose's advice for treating flares on or around the lips include "keeping them well moisturized with a hypoallergenic, fragrance-free lip balm."

For symptoms like itchiness, swelling and redness she notes that an over-the-counter cortisone cream can help, but advises it's best to "see a board-certified dermatologist for an evaluation if things are worsening or not improving after a few days."

Can eczema on the lips cause long-term issues?

With proper treatment, you can manage eczema flares on the lip area. However, there are some long-term issues that can arise from constant flares on the lips since flares lead to a compromised skin barrier. "Chronic eczema of the lips can cause post-inflammatory pigmentary changes, textural changes and even scarring," said Dr. Rose.

1. Tucker D, Masood S. Seborrheic Dermatitis. [Updated 2023 Feb 16]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2024 Jan-. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK551707>.

Does the Amount of Water You Drink Affect Your Eczema?

By Angela Ballard, RN

Dry skin is a common eczema trigger. If skin gets too dry, it can easily become brittle, scaly, rough or tight, which can lead to an eczema flare. This is why moisturizing with eczema-friendly ointments and creams is a key component of daily eczema management.

But what about drinking a lot of water? Can water consumption help reduce eczema symptoms? Does the amount of water you drink increase the amount of moisture on your skin? Is there a connection between hydration on the inside of your body and the moisture of your skin on the outside?

While these might seem like relatively logical assumptions, experts we spoke with indicated there isn't scientific data to back up the idea that increasing internal hydration beyond normal levels leads to more hydrated skin and fewer eczema symptoms.

What does the data say?

"The effectiveness of adequate water intake as a measure to treat dry skin is still under debate," said Dr. Paul Yamauchi, a cosmetic, medical and surgical dermatologist in private practice at the Dermatology Institute & Skin Care Center in Santa Monica, California.

In a 2023 study on atopic dermatitis and optimum water intake, researchers found that among people with lower than normal water intake, additional water intake did increase hydration in the top layers of the skin.¹ But, for those already consuming the recommended fluids, there is very little data to suggest an added benefit to drinking more, and there is no published data on the effects of fluid intake and skin hydration in children.

1. Douladiris N, Vakirlis E, Vassilopoulou E. Atopic Dermatitis and Water: Is There an Optimum Water Intake Level for Improving Atopic Skin?. *Children (Basel)*. 2023;10(2):273. Published 2023 Jan 31. doi:10.3390/children10020273. 2. Report Sets Dietary Intake Levels for Water, Salt, and Potassium To Maintain Health and Reduce Chronic Disease Risk. National Academies Sciences, Engineering, and Medicine. <https://www.nationalacademies.org/news/2004/02/report-sets-dietary-intake-levels-for-water-salt-and-potassium-to-maintain-health-and-reduce-chronic-disease-risk>. Published February 11, 2004. Accessed January 17, 2024. 3. Urology Care Foundation. The Meaning Behind the Color of Urine. <https://www.urologyhealth.org/healthy-living/care-blog/2018/the-meaning-behind-the-color-of-urine>. Published August 22, 2018. Accessed January 17, 2024.



How much water should you drink?

Whether you have eczema or not, you should drink the recommended amount of water determined by the Institute of Medicine, part of the National Academies of Sciences, Engineering and Medicine, said Dr. Yamauchi, who is also a clinical assistant professor of dermatology at the University of California, Los Angeles. However, "don't over consume water," he added. "You will simply urinate it out, and excessive consumption could lead to a [potentially dangerous] imbalance of electrolytes. The best and proven way to hydrate your skin is applying a good moisturizer every day, after showering or bathing."

The Institute of Medicine of the National Academies indicates that the average adult should consume about 3 liters of water per day through fluids and hydrating foods.² That's 2.7 liters for women and 3.7 liters for men, with increased amounts needed in hot weather or to replenish excess exercise-induced sweating.²

Another simple way to figure out how much water you should drink is to "take your weight in pounds and divide it by two, and that's the amount of water in ounces that you should aim to consume per day," said Victoria Garcia-Albea, a dermatology nurse practitioner at Lahey Clinic Dermatology in Burlington, Massachusetts. "Even coffee and tea count, but avoid excess amounts of sugary drinks and alcohol, which can increase inflammation. If you consume the recommended amounts, there is no solid evidence that drinking more will help your eczema or even that drinking less will make your eczema worse."

Wondering if you're getting enough water? Check your urine. When you're hydrated, your urine should be clear or very light in color, according to the Urology Care Foundation.³

Caring for Eczema on Nipples and Genital Areas

By Mollie Barnes

This latest edition of Ask the Ecz-perts focuses on how people of every gender can handle eczema on sensitive areas such as the nipples and genitals. Our expert discusses how to handle itching, what lotions and medications you can use and precautions you can take to prevent flares in these areas.

Our expert is Dr. Peter Lio, a dermatologist and clinical assistant professor of dermatology and pediatrics at Northwestern University, and also the co-founder and co-director of the Chicago Integrative Eczema Center.

MEET THE ECZ-PERT



Dr. Peter Lio

Clinical Assistant Professor of Dermatology & Pediatrics, Northwestern University Feinberg School of Medicine

Co-founder and co-director, Chicago Integrative Eczema Center

If you have eczema on your nipples, what can you do to stop the itching?

Dr. Peter Lio: Eczema involving the nipples is actually very common. It can affect any age group and can be worsened by rubbing or irritation from clothing. It's important not to scratch, pull or pick [at the nipples] because the tissue there is more delicate in some ways and is liable to [break] open, which can lead to infection.

Importantly, we want to try to use the same principles that we would use to treat eczema on any other part of the body: [using] gentle skincare, good moisturizing [practices] and anti-itch/anti-inflammatory topical medications, when necessary.

What medications or lotions are OK to put on nipples?

Dr. Lio: The nipples are more sensitive than other parts of the body, but they are probably not as sensitive as something like the area around the eyes or lips. However, it's not a bad idea to use the same guiding principles that we would for those most sensitive areas.

Typically, I prefer to use heavy ointments that are more protective. Lightweight lotions (that contain a lot of water) are easier to apply, but tend to protect less, and sometimes can cause stinging and burning.

We also want to avoid or minimize super-potent topical steroids. The tissue [on the nipples] is somewhat delicate and generally more mild preparations are fine. Topical nonsteroidal agents are ideal here, as well. Things like tacrolimus and crisaborole can be very helpful.

How do you manage itching in private parts in public?

Dr. Lio: [That is] a very common and yet surprisingly difficult problem, to be sure! It can drive people crazy trying to get it better, and there are many factors that can make it worse such as, personal care products, detergent residue in clothing and the heat and humidity in the [private] areas.

It's such a common problem that a wonderful paper published back in 1983 listed 10 rules designed to help with itch in the anal and genital areas.¹ Some of the highlights from the paper include:

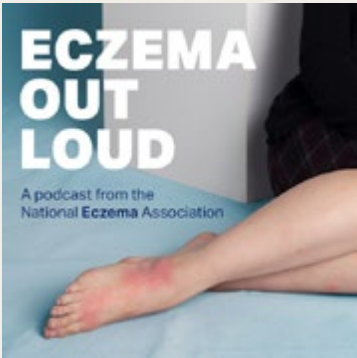
- Keep the area clean by washing after every bowel movement, at night and in the morning
- Avoid rubbing the area with soap or a washcloth
- Keep the area dry, avoid excessive moisture
- Wear cotton underwear and loose-fitting clothing
- Avoid perfumed talcum powder or ointment and creams, unless prescribed by your dermatologist

What medications or lotions are OK to put on the vagina, penis, scrotum, etc.? Is it safe to put topical steroids on those areas?

Dr. Lio: We have to be most careful as the skin of the genital area is extremely thin and unlike that on the rest of the body. It's important to check with a licensed healthcare provider, and ideally one who understands the nuances of treating these areas, before using any prescription medications to those areas.

Like with the nipples, heavier ointments tend to be better tolerated and more protective rather than lightweight lotions or creams.

It is very important to avoid getting medications, or even non-prescription topical preparations, in the vagina, mouth or anus, as the tissue is very different inside.



Listen to our podcast on eczema on genitals

For more information, listen to Dr. Peter Lio talk about ways to treat and manage eczema on nipples and genitals on our podcast, Eczema Out Loud.



Do you suggest using any special soaps or lotions for private parts?

Dr. Lio: Very gentle is the key! Harsh soaps can cause dryness or irritation of the sensitive skin on the private parts, so things that are designed for sensitive skin are best. I'm a proponent of oil-based cleansers and many companies now have them available. A great place to start is the National Eczema Association's Seal of Acceptance™ Product Directory.

Are there certain types of undergarments you should wear to lessen eczema flares or itch in private areas?

Dr. Lio: Yes, soft cotton underwear is best. For many patients, synthetics are irritating and sometimes they can retain more heat and moisture in the area.

¹. Alexander-Williams J. Causes and management of anal irritation. *Br Med J (Clin Res Ed)*. 1983;287(6404):1528. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1549920/pdf/bmjcred00581-0040.pdf>. Accessed February 6, 2023.

RESEARCH

New Paper on the Definition of an Eczema Flare

By Angela Ballard, RN

The word “flare” is often used in discussion of atopic dermatitis (AD) or eczema. But what exactly is an eczema flare and how do people living with eczema describe flares?

The research team at the National Eczema Association (NEA) conducted a study to investigate the definition of flare, which was recently published in the *British Journal of Dermatology* in January 2024.

“When it comes to atopic dermatitis, flare is a nearly ubiquitous term,” said Wendy Smith Begolka, co-author of the study and chief strategy officer at NEA.

Generally, the term “flare” describes a worsening of symptoms. It’s a word used in conversations between patients and healthcare providers and one used to gauge if eczema is being well managed or if a particular treatment is having an impact.

“But there’s actually no single standardized definition of an eczema flare and no definition that incorporates patients’ lived experiences and perspectives,” Smith Begolka said. “In this study, we wanted to get closer to what ‘flare’ actually signifies to people with AD.”

Research methods







As part of the study, the researchers conducted online focus group discussions with 29 adults with AD. Participants were volunteers from the NEA Ambassadors program, mostly female (69%), Asian or Asian American (35%), 18–35 years old (62%) and diagnosed with AD in childhood (83%). All participants self-reported moderate or severe AD when their AD is at its worst.

In the focus groups, participants talked about how they describe AD flares, how they recognize a flare’s beginning and ending and how they relate to current flare definitions. Transcripts of the conversations were then analyzed.



Key takeaways

While more work on this topic is needed, analysis of focus group discussions revealed six themes on what patients felt were important in a flare definition. They include:

-  A change from the person’s perceived baseline or “normal”
-  Mental, emotional and social consequences of flares
-  Physical changes in the skin
-  Increased demand for and focus on management of their AD
-  Experiencing the itch-scratch-burn cycle
-  Loss of control and loss of some quality of life related to the flare

Patients also associated the experience of having a flare with trying to figure out the cause of the flare, but they did not feel that this was part of the definition.

According to the focus groups, existing definitions of “flares” that have been used in research and clinical trials do not adequately reflect their experiences because these definitions often:

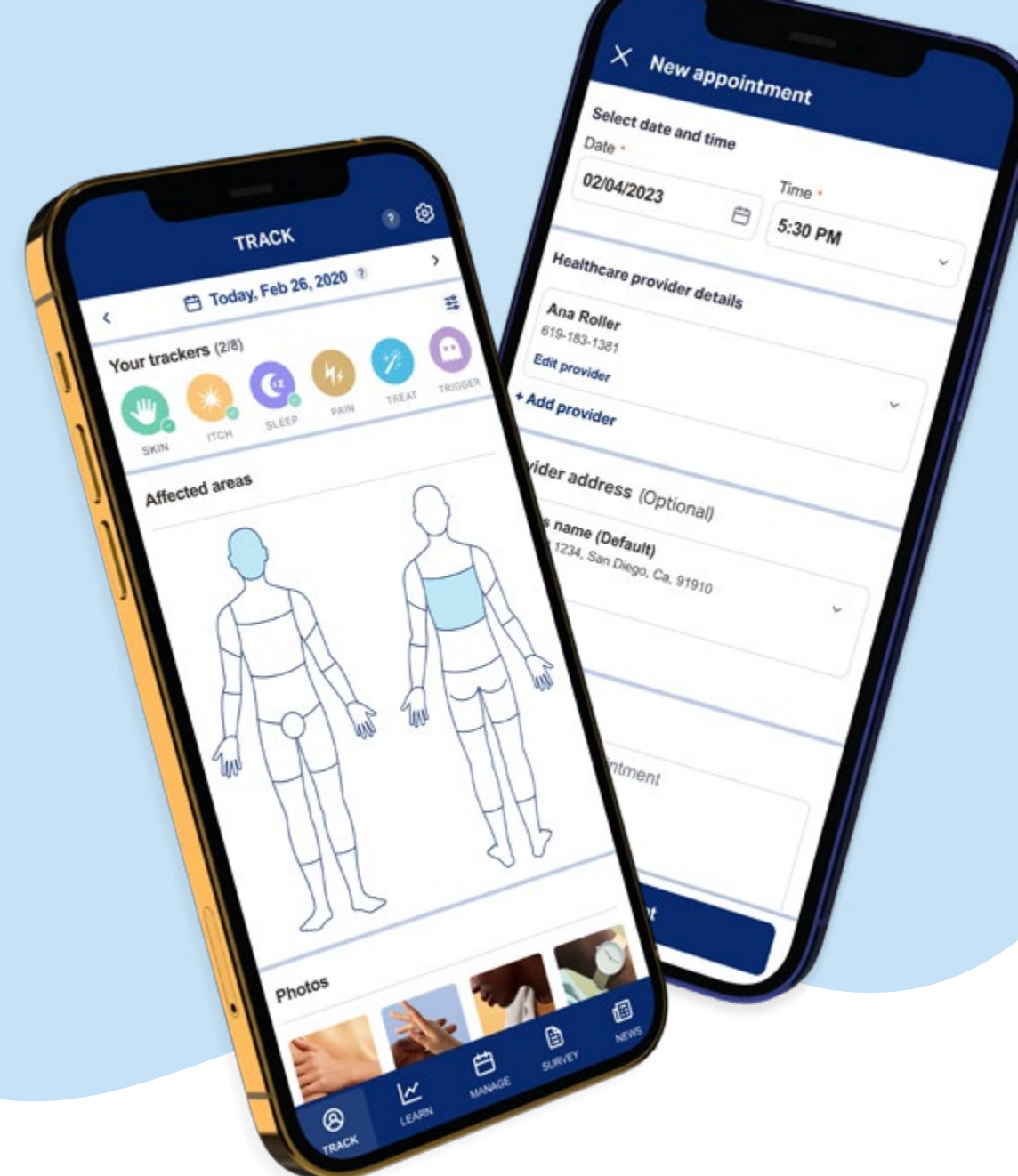
- Incorporate numeric scales which are difficult to apply to multi-dimensional experiences
- Focus solely on the skin, neglecting other aspects of a real-life flare
- Include language that’s “too clinical” to be fully relevant from the patient perspective

Why this research matters

The results of this study highlight the complexity and diversity of AD flare experiences from adult patient perspectives and how current definitions of flares do not resonate with many people with eczema.

“As one study participant told us, ‘a flare is deeper than the skin,’” said Smith Begolka. “Better understanding of this can improve patient-provider communication, relationships and shared decision making.”

The NEA research team is continuing to work on this important topic. The end goal is to eventually have a shared language between patients, healthcare providers and treatment developers about AD flares.



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