



National  
**Eczema**  
Association

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# NEA Magazine

Research, Support and Education for Those Affected by Eczema

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artwork

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Eczema is as unique as your child. Turn your **whys** into **wise**.



## NEA Magazine

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### 5 Terms Your Dermatologist Uses You Might Not Understand

Have you ever left an appointment with your dermatologist feeling confused by the medical jargon? You're not alone. Dust off those vocabulary skills with a few key terms.

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 Julie

Welcome to the spring issue of NEA Magazine! Here at NEA headquarters we are thrilled to usher in the new season and showcase the many new developments in our community.

We're only months away from our first in-person Eczema Expo since 2019 and I can't wait to be with you again in real life. It's taking place July 7-10 in Seattle, Washington — check out [EczemaExpo.org](https://EczemaExpo.org) for all the details and to register. And for those unable to be there in person, we'll continue to offer a virtual platform that will allow access to most sessions.

Other conferences are also back in person and the NEA research team is making the rounds with new posters and presentations, amplifying the true lived experience of patients and caregivers. Most recently, we shared findings of our community research on atopic dermatitis clinical trials, out-of-pocket costs for patients and access barriers to treatments at the American Academy of Dermatology (AAD) conference in Boston — and we presented at the Revolutionizing Atopic Dermatitis conference in Baltimore from April 9-11.

In the past few months, we've also seen three new eczema treatments approved by the FDA. While exciting, it has also raised many important questions from our community. To help you navigate the evolving new treatment landscape, we've included "What Does A Black Box Warning Mean for Eczema Treatments?" on page 8. We've also included "5 Terms Your Dermatologist Uses You Might Not Understand" on page 26 to help you become more confident about the vocabulary of eczema before heading into your next doctor appointment.

On page 24, we showcase a new collection of artwork from you, our eczema community. It's such a treat and honor to see your stories come to life visually.

Spring adds new life and new beauty to all that is, and I send my wishes that it is just so for you!

With warmth & gratitude,

Julie Block - President & CEO

**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

## Eczema Expo 2022, NEA Ambassadors, Why I Give, Itching for a Cure & Research Conferences

### Eczema Expo 2022

Registration is open for Eczema Expo at [EczemaExpo.org](https://EczemaExpo.org).

After two years of virtual events, we are finally ready to reconvene Eczema Expo in person – and we want you to be there! In 2022, Eczema Expo will be a hybrid event, with the in-person portion taking place in Seattle, WA from July 7-10.

We are committed to making Expo accessible to as many people in the eczema community as possible.

Expo fundraising offers attendees the opportunity to run a peer-to-peer fundraising campaign to offset costs of Expo registration, travel and hotel. Find out more about getting help paying for Expo. And mark your calendar for the eczema event of the year!

We'll see you in Seattle!

### NEA Ambassadors' Corner

NEA Ambassadors continue to be active in their communities raising eczema awareness. Some of the activities we're most excited about are:

- **Itching for a Cure Campaign (May 2-16)** – Ambassadors will again join forces to raise \$20,000 for the NEA Research Fund. All donations raised will be invested in groundbreaking eczema research;
- **NEA's first Virtual Hill Day (June 7-8)** – an exclusive Ambassadors-only opportunity to meet virtually with legislators to spread eczema awareness and advocate for improved access to care, as a team.

Join NEA Ambassadors to create change in eczema research that will lead to better treatment, advocacy that will get us closer to better access to treatments and awareness that will inform the larger community about eczema's true burdens!

Become an Ambassador to make sure your voice is heard.

### Why I Give

My name is Nitin Dogra, and I live in Herndon, Virginia. I have had eczema for 20 years. My wife and my 3 year-old twin boys also have eczema.

### This is, in my opinion, the hardest thing about living with eczema

For me the hardest thing about living with eczema are all the limitations on the movement and activities I can do. My chronic eczema means I have to be mindful about what I can eat and what I can wear. I have to wear cotton pajamas because of the eczema on my legs. I got thinner because of limiting the foods I eat. Traveling



Nitin Dogra pictured with his family.

is especially hard; I have to have moisturizer with me and a place to moisturize always.

I remember walking from the parking lot to my office feeling disabled because walking was hard with the bruises and pain in my legs. I was 30 years-old but walking like somebody who was 80.



People judged me for not looking good and made me feel not good enough. I limited my social circle, choosing to hide away and avoid situations instead.

It takes a toll on me. It took me a long time to accept it. Mentally, I started to feel depleted.

This is why I give to NEA

I give to NEA out of a sense of feeling the pain of others and wanting to help them.

When I started getting the NEA magazine, it really hit me, “Here’s an organization putting a concerted effort into helping with a condition I have had for so long.” I felt a sense of community reading all these stories of other people going through the same thing. It was like reading a good book and feeling inspired.

Every year on my sons’ birthday we ask for donations to NEA in their honor. It’s become a ritual.

It gives a meaning to the suffering my family and I have experienced because of eczema. On my sons’ birthday, we are doing something that includes others. Those donations will be beneficial to the whole NEA community.

This is my hope for the future of eczema

I hope there are safer treatments with less complications that relieve symptoms in a shorter time period. I wish doctors would better understand and communicate more openly about the repercussions of topical steroid use and the importance of diet. I also hope patients feel more ownership over how to care for themselves. I wish for a sharing of wisdom that helps us heal ourselves.

Itching for a Cure

The 2022 Itching For A Cure (IFAC) campaign is happening from May 2-16.

At NEA, we drive research in two ways: we fund research through our annual grant program, and we conduct our own research. NEA is the largest private funder of eczema research in the country, providing much-needed grant support to the most dedicated doctors and scientists in the field.

We ensure the voice of people living with eczema is front and center across our growing research program.

This year's goal is to raise \$20,000 for the NEA Research Fund. All donations will be invested in eczema research. Join us!

We're looking for your help to make donations, fundraise and spread the word on social media.

Contact NEA's Development Director Rachel Lee Holstein at [RachelLee@NationalEczema.org](mailto:RachelLee@NationalEczema.org) if you'd like to get involved.

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NEA Research

The NEA Research team is back on the conference circuit now that posters and presentations are taking place in person again. NEA's Allison Loiselle, Isabelle Thibeau, Wendy Smith Begolka, Jessica Bartolini, Lisa Butler and Julie Block all attended the American Academy of Dermatology's annual meeting in Boston, MA from March 25-29. The NEA team presented from our own NEA research findings on out-of-pocket expenses, clinical trial experiences and prescription treatment access.

The NEA Research team also attended the Revolutionizing Atopic Dermatitis (RAD) conference from April 9-11 in Baltimore, MD. NEA's Wendy Smith Begolka took part in a moderated symposium on the assessment and management of itch in atopic dermatitis.

We're also pleased to announce that the next cycle of applications for the NEA Research Grant will be opening in early May. Email [Grants@NationalEczema.org](mailto:Grants@NationalEczema.org) for more details and any questions you may have.

GET AHEAD OF ECZEMA  
AND SHOW MORE SKIN

DUPIXENT is a breakthrough eczema treatment that targets a key source of inflammation that can lead to uncontrolled moderate-to-severe eczema (atopic dermatitis).

Approved for ages 6 years and up.

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- ▶ Clearer skin that lasts\*
- ▶ Not an immunosuppressant
- ▶ Not a cream or steroid

\*In a clinical trial at week 16, 59% of adults taking DUPIXENT + topical corticosteroids (TCS) had significantly less itch vs 20% on TCS only; 39% saw clear or almost clear skin vs 12% on TCS only. 36% saw clear or almost clear skin at week 52 vs 13% on TCS only.

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Individual results  
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**DUPIXENT®**  
(dupilumab) Injection  
200mg • 300mg

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INDICATION

DUPIXENT is a prescription medicine used to treat adults and children 6 years of age and older with moderate-to-severe atopic dermatitis (eczema) 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 years 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 atopic dermatitis include** injection site reactions, eye and eyelid inflammation, including redness, swelling, and itching, sometimes with blurred vision, and cold sores in your mouth or on your lips.

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](http://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 under 12 years of age, DUPIXENT should be given by a caregiver.

Please see Brief Summary on next page.

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# WHAT DOES A BLACK BOX WARNING MEAN FOR ECZEMA TREATMENTS?

by **Jodi L. Johnson, PhD**, Departments of Dermatology and Pathology, Feinberg School of Medicine, Northwestern University



All medications have drug labels and packaging inserts that provide important information on safe and proper medication use. This information includes how to use medications, who should not use them, things to avoid when taking certain medications and the risks of possible side effects (also known as adverse events).

All medications carry some risk of side effects, which can range in severity from relatively minor to more serious. Medications with a risk of serious side effects can be issued a boxed warning, also known as a “black box” warning by the U.S. Food and Drug Administration (FDA).<sup>1</sup> Several drugs used to treat atopic dermatitis (AD) have a boxed warning label (Table 1). In this article, we will discuss what these labels mean and how you can discuss this information with your healthcare provider when considering and selecting treatment options.

## WHAT IS A BOXED WARNING AND WHY DOES THE FDA USE IT?

A boxed warning can be issued by the FDA for newly approved or existing drugs to highlight one of the following situations for healthcare providers and their patients if:<sup>2,3</sup>

- ➔ There is potential for a serious adverse event when compared to the potential benefit from the drug; risks and benefits must be carefully weighed;
- ➔ A serious adverse reaction can be prevented or reduced by appropriate use of the drug (e.g., patient selection, careful monitoring, avoiding using certain other medications at the

same time, monitoring the dose of the drug, or avoiding use in a specific clinical situation);

- ➔ The FDA approved the drug with certain restrictions for use and distribution.

The FDA collects drug safety data for all phases of clinical trials, including Phase IV, after a drug has been approved and is being used in the real world by different types of patients.<sup>1</sup> While many common but tolerable or manageable side effects (such as headache or upset stomach) may be readily apparent during Phase I-III clinical trials, other more severe effects may be rare and, if they do not become apparent in the early phases, may become apparent in Phase IV when large numbers of people use the medicines.

If evidence of serious adverse events associated with a medication increases, the FDA may consider continued monitoring or a boxed warning and, if higher numbers of these events occur over time, may remove the drug from the market altogether.<sup>1</sup>

The FDA started using the boxed warning label in 1979<sup>1</sup> and has, as of September 2019, placed the warning label on over 400 different medications, including those delivered topically, orally, by injection or through other delivery methods. Figure 1 depicts an example boxed warning label for Opzelura, a topical Janus kinase inhibitor (JAK) approved for use in AD.

Dr. Kendall Marcus, director of the division of dermatology and dental products at the FDA provided some insight into these warnings, “Boxed

warnings are prominently placed as the first section in the prescribing information for healthcare providers and contain a summary of the essential scientific information needed for the safe and effective use of the drug.”<sup>2,3</sup>

Dr. Marcus went on to say, “The prescribing information must be updated when new information becomes available that causes the labeling to become inaccurate, false or misleading.”<sup>3</sup> The FDA has stated that if the criteria for including a boxed warning are no longer met, it is reasonable to modify or remove the boxed warning based on clinical data.”

## BOXED WARNINGS AND MEDICATIONS FOR AD

Several medications used in the treatment of AD carry a boxed warning, including the new FDA-approved topical and oral JAK inhibitors (Table 1). However, medications that carry a boxed warning can be important treatment options – highlighting an important opportunity for patient-healthcare provider discussions regarding potential risks of a therapy alongside the anticipated benefits.<sup>5,6</sup>

Drug Name	Brand	Drug Delivery Method
Abrocitinib	Cibinqo™	Oral
Cyclosporine	Neoral®	Oral
Methotrexate	Trexal®	Oral
Mycophenolate mofetil	CellCept®	Oral
Pimecrolimus	Elidel®	Topical
Ruxolitinib cream	Opzelura™	Topical
Tacrolimus	Protopic®	Topical
Upadacitinib	Rinvoq™	Oral

Dr. Eric Simpson, of Oregon Health and Science University, said, “The black box is there for a reason – either a perceived or real risk as determined by the FDA – but the dangerous side effects mentioned on the label are often rare. A lot of times whether to still use a drug with a boxed label depends on the context. The most important thing is to discuss whether benefits outweigh risks in a particular situation taking into account disease severity, other medical problems, age and other treatment options that may be available. Then together, patients and healthcare providers can make informed decisions about whether these highly effective medications are right for the circumstance.”

Examples of the importance of context can be illustrated by looking at two different drug classes used for AD treatment, calcineurin inhibitors and JAKs.



HIGHLIGHTS OF PRESCRIBING INFORMATION  
These highlights do not include all the information needed to use OPZELURA cream safely and effectively. See full prescribing information for OPZELURA cream.

OPZELURA™ (ruxolitinib) cream, for topical use  
Initial U.S. Approval: 2011

**WARNING: SERIOUS INFECTIONS, MORTALITY, MALIGNANCY, MAJOR ADVERSE CARDIOVASCULAR EVENTS (MACE), AND THROMBOSIS**

See full prescribing information for complete boxed warning.

- Serious infections leading to hospitalization or death, including tuberculosis and bacterial, invasive fungal, viral, and other opportunistic infections, have occurred in patients receiving Janus kinase inhibitors for inflammatory conditions. (5.1)
- Higher rate of all-cause mortality, including sudden cardiovascular death have been observed in patients treated with Janus kinase inhibitors for inflammatory conditions. (5.2)
- Lymphoma and other malignancies have been observed in patients treated with Janus kinase inhibitors for inflammatory conditions. (5.3)
- Higher rate of MACE (including cardiovascular death, myocardial infarction, and stroke) has been observed in patients treated with Janus kinase inhibitors for inflammatory conditions. (5.4)
- Thrombosis, including deep venous thrombosis, pulmonary embolism, and arterial thrombosis, some fatal, have occurred in patients treated with Janus kinase inhibitors for inflammatory conditions. (5.5)

Figure 1: From Opzelura™ Prescribing Information.

## TOPICAL CALCINEURIN INHIBITORS

The topical anti-inflammatory calcineurin inhibitors (TCI) tacrolimus and pimecrolimus were approved as topical ointments and creams for treatment of AD in 2000 and 2001, respectively.<sup>7</sup> These medications added much needed alternatives to topical steroids and topical corticosteroids as new treatment options for AD. They can be used for short-term and longer-term non-continuous use to treat mild, moderate or severe AD in non-immunocompromised adults and children over 2 years-old who have not responded to other topical treatments. However in 2005, several years after the drugs had been approved for AD, the Pediatric Advisory Committee of the FDA added boxed warnings for these TCIs that remain today. The warning states, “Long-term safety of topical calcineurin inhibitors has not been established. Although a causal relationship has not been established, rare cases of malignancy (e.g., skin and lymphoma) have been reported.”<sup>7</sup>

Data supporting this boxed warning were largely established from cell culture studies, animal models and data from prolonged systemic use in transplant patients. Since 2005, however, studies conducted with cohorts of thousands of AD patients in the U.S. have not found increased rates of skin cancer or lymphoma. A few cases of skin cancer after TCI use have been reported in older adults (>55 years old), but the case reports did not include details of earlier treatments or other factors that could have been associated with these cancers.<sup>7</sup>

A 2015 publication analyzing pediatric AD patients enrolled in the Pediatric Eczema Elective Registry (PEER) with a history of AD and pimecrolimus use showed no statistically significant association between the treatment and malignancy.<sup>8</sup> An updated literature review published in 2019 with increased data collected over time concluded that “the benefits of TCIs outweigh their potential risks when used in the appropriate patient populations for the recommended duration of time.”<sup>9</sup> Another definitive long-term (10 years) study was recently published (2020) on the use of tacrolimus in children. The study concluded, “This finding provides no support for the hypothesis that topical tacrolimus increases long-term cancer risk in children with AD.”<sup>10</sup>



It is important to understand what data led the FDA to issue the boxed warning and how subsequent published studies add to the broader understanding of risks in the real world. The incidence of the side effects, what kind of patients they occurred in and at what drug doses should also be considered. Dr. Peter Lio, of Northwestern University, stated, “Black box labels by themselves do not tell us how likely risks are for a given patient. Further, risks on black box warnings often seem to be dose-related to some degree. In fact, tacrolimus, pimecrolimus and the newer ruxolitinib cream (a topical JAK inhibitor) have language to the effect of limiting use. The prescribing information for ruxolitinib cream says to use it for ‘up to 20% body surface area’ and ‘do not use more than 60 grams per week.’ It seems likely that when used in relatively small quantities, the absolute risk for some of the boxed warnings to AD patients is low.”

JANUS KINASE INHIBITORS (JAKs)

Though oral JAK inhibitors have been approved for the treatment of inflammatory diseases, such as rheumatoid arthritis, for several years, the FDA has recently approved a topical JAK inhibitor (ruxolitinib [Opzelura™] cream) and two oral JAK inhibitors (upadacitinib [Rinvoq™] and abrocitinib [Cibinqo™]) for treatment of AD.<sup>11-13</sup> These drugs represent the latest new therapies supported by decades of research to identify and target the immune pathways that contribute to AD. They provide patients and healthcare providers with additional options for different severities of disease.<sup>14,15</sup>

As these drugs were in the process of being reviewed by the FDA for use in AD, the FDA began revising the boxed warning label for the entire class of JAK inhibitors.<sup>5</sup> Rare side effects seen after systemic use of drugs like tofacitinib (Xeljanz®) to treat rheumatoid arthritis resulted in even topical JAK inhibitors receiving the boxed warning. Dr. Raj Chovatiya, PhD, of Northwestern University, said, “The JAK inhibitor class of topical and oral medications have been given a label for risks including mortality, infections, malignancy, major adverse cardiovascular events and blood clots. These warnings are based on data from a long-term, randomized, post-marketing study (Phase IV) assessing safety of tofacitinib versus tumor necrosis factor alpha (TNFα) inhibitors in patients with rheumatoid arthritis.<sup>16</sup> While most of these adverse events appear to be uncommon in AD patients treated with JAK inhibitors, some were still observed in rare instances – often without clear relation to the medication itself. Thus, while JAK inhibitors appear to be highly efficacious with favorable safety in AD patients, more data and more time is needed to better understand this over the long run.”<sup>17,18</sup>

More studies are needed to understand similarities and differences between AD patients and patients using JAK inhibitors for other diseases like rheumatoid arthritis. While common immune system pathways may be shared across different inflammatory diseases, affected patients may have different co-occurring conditions that affect overall risk of side effects (such as cardiovascular disease in rheumatoid arthritis patients).<sup>17,18</sup>

Though studies in AD patients are limited to clinical trials, so far, the adverse events represented on boxed warnings have only very rarely been seen.<sup>19,20</sup> This is an example of a type of drug class whose benefits may outweigh the risks in AD patients with the recommended dosing, avoiding or limiting use in patients with higher risks for side effects and with monitoring over time.

SHARED DECISION MAKING –  
A CONVERSATION ABOUT MEDICATION  
RISKS AND BENEFITS

The concept of “shared decision making,” a growing movement in patient-centered care, is broadly defined as patients and caregivers working with healthcare providers to better understand their condition and treatment options to align on healthcare decisions together.

While understanding the risks and benefits of medications is a component of all shared decision making conversations, the presence of a boxed warning elevates the importance of this discussion in arriving at a treatment decision. Dr. Marcus said, “Boxed warnings will typically include steps to take to prevent, reduce, monitor for or manage clinically significant adverse reactions or risks, therefore allowing for the safe and effective use of the drug.”

So, what would that conversation with your healthcare provider look like? Dr. Peter Lio and Dr. Raj Chovatiya both weighed in on positive doctor-patient conversations around these issues. First, we asked both doctors to comment on what factors they consider when evaluating a medication with a boxed warning, and how the presence of this warning impacts the conversation they have with patients.

**Dr. Lio:** “Sometimes a patient’s eczema can be effectively treated with gentle, safer treatments and medicines, but if those treatments are not adequately treating the disease, we consider more powerful treatments, even in the face of some risk. Untreated or under-treated eczema has its own set of side effects and risks, so for some patients the risks of taking a particular medication are outweighed by its potential benefits.

Since there have been so few approved drugs to treat eczema, the dermatology healthcare community does use medications with black box warnings frequently. In general, the more powerful the treatment, the more likely there are side effects. As physicians, we never want to be dismissive or undermine an FDA warning. Reading the scientific data and Prescribing Information for how to use the drug to treat a disease like eczema influences our recommendation of a certain medication.

We want to be honest, open and accurate about the safety and risks of these medications for our patients and their families. I often say, ‘Let’s discuss the burden of the disease, the different treatment options, what we have so far tried and what treatment goals we are trying to achieve by using this medicine, plus what dose we will be prescribing.’”

**Dr. Chovatiya:** “I leave extra time for questions and discussion so a patient will feel comfortable in the decisions we make together. Many patients with AD do not have adequate control of their disease,



*underscoring the need for additional effective treatments. As our armament of topical and systemic therapies for AD becomes richer, so will the individual shared decision making conversations that accompany each potential treatment option. Black box warnings are an important mechanism used to highlight certain serious risks that may be associated with a particular drug or treatment class. While these adverse events are generally rare overall and/or associated with only certain risk factors, they are still important to discuss alongside efficacy, safety and patient preference (e.g., feasibility, cost, route of delivery) when helping an individual with AD select the most appropriate therapy.*

Eczema is not a one-size-fits-all disease,  
and neither are treatments and their  
associated risks.

*When we feel comfortable with the balance of risks and benefits, I work my hardest to make sure that we do everything possible to get the best treatment on board – with ‘best’ meaning very different things from case to case. As an example, a patient who has not had previous success with other therapies, may decide that a therapy with a boxed warning might in fact be the ‘best’ to help them achieve disease control.”*

Some medications with boxed warnings might require monitoring for potential side effects. We asked the doctors about the different approaches they use.

**Dr. Lio:** “For most patients, I am happy to say, even the ‘scariest’ medications can be used safely and can bring great relief. Each medication has different considerations. For example, for our topical treatments, the key thing is to keep an eye on how much medication is being used. For me, I will look at the number of refills obtained between visits. Topical ruxolitinib only comes in 60 gram tubes so the recommended dose would be a full tube every week! It would be nearly impossible for the majority of patients to get a fresh tube every week. Therefore, patients are using less than the dose that led to the warning label for this medication.

# LEO Pharma

**At LEO Pharma, our vision is to be a preferred medical dermatology care partner. We have been working to improve people’s lives around the world for more than 100 years. We are proud to support the National Eczema Association’s efforts to reduce the burden of eczema through research and education that enhance care and improve patient outcomes.**

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*For the oral agents, we do things like blood testing to check the kidneys, liver, platelets and blood count. For medications like cyclosporine (sometimes used off-label for AD) we also check for elevated blood pressure. In addition to this monitoring, patients can reach out to healthcare providers if they are experiencing harmful side effects so adjustments can be made to the treatment plan.”*

**Dr. Chovatiya:** *“First we do a thorough assessment of past medical history and review of systems. This is the most important way to monitor for any changes in health status while on therapy. Each medication has unique considerations and physicians are expected to closely read and understand the prescribing information and monitor for changes in medical labels to follow the best clinical practices. Depending on the drug in question, lab monitoring can be a helpful strategy. In the case of JAK inhibitors, we can include assessment of blood count, liver function and lipids at various points throughout therapy, as well as baseline assessment of tuberculosis and viral hepatitis status.”*

Selecting a treatment approach is an important decision, and one that can raise a number of questions. We asked the doctors for their suggestions/recommendations for patients and caregivers as they think about whether to use treatments that have boxed warnings.

**Dr. Chovatiya:** *“AD is associated with an immense burden for patients and choosing the right treatments over time is a major part of this. There really is no right or wrong answer, and each conversation is highly dependent upon someone’s disease severity, comorbidities and previous treatment approaches. Boxed warning or not, I want to encourage patients to take the appropriate time to understand and feel comfortable with both how well a drug works and how safe it is. Patients should be open with providers when it comes to personal concerns and points of view. There is no such thing as a bad question – if you’re thinking about asking it, odds are many other patients have felt the same way.”*

**Dr. Lio:** *“No medication should be used forever and I like to make sure we’re checking in frequently, re-evaluating and changing the treatment approach to meet the current needs of the patient and address the current state of the disease.”*

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CONCLUSIONS

We are at an exciting time in the treatment of AD, with several newly FDA-approved options available, and many more in the development pipeline. Despite the presence of boxed warnings for some existing and new treatments, these medicines add much needed tools to the toolbox needed to treat AD. This article highlights the importance of data and context as healthcare providers and patients work together to formulate treatment plans that take into account the risks and benefits of the medication, patient heterogeneity, individual preference and risk tolerance.

TAKE HOME POINTS

- All medications come with the risk of potential side effects that can range from mild to moderate or severe.
- The FDA is responsible for the safety of people taking approved medications for their intended use and errs on the side of caution when warning of severe side effects, even if rare.
- Warnings about the most severe potential adverse effects appear as boxed labels ('black box') on the medication and in the Prescribing Information.
- Understanding what dose, delivery method, duration of use and patient characteristics (age, sex, health history, other medications) are indicated in a boxed warning can help you and your health care provider weigh the risks and benefits of taking the drug.
- Many new drugs are in development for use for AD and their risks and benefits, as determined in clinical trials, may change as the drug becomes broadly used.
- Determining your individual comfort level with the risks of each medication balanced against the potential benefits will help you and your healthcare provider align on a treatment strategy for managing AD.



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## MY JOURNEY

# How I Survived 10 Years of Seborrheic Eczema

by Turquoise Peart



**When I was 14 years-old my hair started to fall out because of my seborrheic dermatitis.**

Any time I washed my hair by myself, my scalp would itch so badly I would scratch and scratch. The itching was so bad that I could not stop scratching.

**Because I was in high school, I felt so embarrassed and hoped that no one would notice the scratching. We didn't know what it was.**

Parts of my scalp turned grey around my hairline: it was so noticeable and see-through, and eventually I lost all my hair.

*All photos courtesy Turquoise Peart*

## For more than 10 years, it felt like my scalp was on fire

One of the interesting things about being Black is the various skin hues and hair textures that exist. If you're mixed race, you might have softer texture or curlier hair. My dad is Jamaican and my mom is Trinidadian, and my hair would fall into the category of "kinky," which requires straightening or a lighter, spongy and more manageable hair texture. Being a person of color can sometimes mean we have a naturally drier scalp, and because it's dry already, at least for me, it accelerated the itch-scratch-cycle because I didn't know what to put on it — anything I tried could potentially irritate my scalp.

My mom owned her own hair salon since she was 19 and tried everything possible to help me get my hair back on track. Our family would ask: "what's going on with her hair?" In my own way, I confidently smiled and assured them everything was okay. As I reflect back, I remember perm-days so vividly when my mother would have to rinse any product off my scalp because of how badly it burned. I had open sores and scabs and when the product was applied to my scalp, it felt like fire and intense burning. On a scale of 1-10, the pain was a 9.5: unbearable. My mother also tried no-lye relaxers.

This went on for about 10 years.

When I was in my early twenties, we finally went to the Cleveland Clinic and I met a dermatologist — I can even remember her name to this day — Dr. Afsa Akshar, who gave me a diagnosis of eczema on my scalp.

## Finally, we knew how to start treating my skin condition

This was the best and most hopeful moment of my life. All of the research and waiting had paid off.

With her help, we started to figure it out. Now, what I do: I don't use those old products anymore; I maintain a care balance with the oil in my skin. And I realized there were certain foods that were making my skin more oily, especially my scalp. For me, after all my research, it was prepackaged foods that triggered my oily skin.

Now, I don't eat any preservatives. I make all my own meals. Anything that has a shelf-life that could outlive me, I'm like: NO. If it's in a bag, I'm going to stay away from it. No sweeteners. Only real food. And that helps me maintain my oil balance.

My mother also helped teach me how important it was to "base" my scalp. For someone who might have seborrheic dermatitis but not yet realize it, I would recommend trying to base your scalp to see if it cools down the itching.

A typical hair regimen for a person of color looks like this: wash your hair, part it and apply sheen; we don't have a lot of oil in our hair naturally, so it replenishes the oil. But with such a sensitive scalp, what works for me is to base my scalp with petroleum jelly on the part, then put product over the top of my hair versus directly on the scalp.

We did that for a few years and it helped. Even now, with my eczema under control, I still base my scalp out of fear.

Anytime you get a relaxer in your hair, you should use a base such as Vaseline. I've noticed that many people only tell you to base your edges and your ears. When relaxing my hair, I based my edges, my ears and my scalp. Basing the scalp has definitely helped stop the burning.

I've now been "in remission" for several years. In 2019, I moved from South Florida to Chicago to pursue new career opportunities. Now I work as the manager of diversity, equity and inclusion & culture for a mortgage lending company. I've discovered that I thrive in cooler climates. South Florida was so humid, but since living in Chicago I've never had a flare-up.

I love Chicago, where I'm constantly surrounded by innovation and progressive thinking.

I've seen other young girls, including a 10-year-old girl in my church, experience what I went through, and I want to help. I want to be an inspiration.

**I want to encourage you not to give up. Keep in mind that with the plethora of skin types and hues of Black skin, you have to love the skin that you're in.**

Love the "oily skin you" or the "dry skin you," and start isolating your triggers one day at a time. Start with your diet, then maybe your hair products (natural hair versus permed), perfumes, fragrances and metals. Ask your doctor for an allergy test to know where to start.

Your story is important. Do not give up.

You are one day closer to your breakthrough and the entire NEA community behind you.

*Author Turquoise Peart is a NEA Ambassador.*



## GET THE FACTS

# Melatonin and Eczema

By Clare Maloney



**With itchy skin, it's hard enough to get a good night's sleep. You can do everything right — create a consistent bedtime routine, moisturize, moisturize again, avoid phone and computer screens before bed, get a good amount of physical activity during the day — and still it feels like your dry skin is conspiring to wake you up at night.**

Many people, both with and without eczema, take melatonin supplements at night to help them get a better night's sleep. However, recent studies have examined not only how melatonin supplements can help you fall asleep, but also how it interacts with the immune system to potentially reduce eczema-related sleep disturbances like nighttime itching.

## Melatonin and the immune system: Don't sleep on this duo

Melatonin is a hormone mainly produced in the pineal gland in the brain. "Like other hormones, it circulates throughout the body and interacts with the immune system. This helps to coordinate the timing of immune system activity," said Dr. Anna Fishbein, associate professor of pediatrics (allergy and immunology) at Northwestern University Feinberg School of Medicine. "Melatonin interacts with the immune system via multiple pathways, such as acting as an antioxidant or acting directly on immune cells via melatonin receptors." Although our bodies produce melatonin naturally, a

melatonin supplement before bed can help provide a sedative effect to fall asleep faster. For people with itchy skin at night, the research shows that the benefits of melatonin may extend beyond simply falling asleep — which could lead to sleeping more soundly, too.

## The science behind sleeping and scratching

According to the More Than Skin Deep "Voice of the Patient" report, a collaborative initiative within the eczema community to inform treatment research and development for atopic dermatitis (AD), sleep ranked third among the top three most problematic symptoms in responses to polling and a survey.<sup>1</sup> This comes as no surprise since sleep disturbance is reported in 47% to 80% of children with AD and in 33% to 87.1% of adults with AD.<sup>1</sup>

"I'd wake every few hours, bloody and in tears because I had ripped everything off in my sleep because my skin felt like it was on fire. It burned and itched and the only thing I could do for relief was to scratch and claw at it, rub it feverishly on anything I could reach," said More Than Skin Deep panelist, Briana Cox.

During sleep, our bodies cycle between four stages: one rapid eye movement (REM) cycle and three non-REM (NREM) cycles.<sup>2</sup> It's common for many people to wake briefly between the cycles. For people with eczema, the pain, dry skin and nighttime itching from

a flare is often enough to wake them up and keep them up. This is in part due to the activation of the immune system during a flare, leading to free radical production associated with decreased melatonin levels and depressed antioxidant enzyme activities.<sup>3</sup>

Temperature can also play a role. At night, our bodies naturally prepare for sleep by cooling our core temperature.<sup>4</sup> "However, this means that in the hour or two before bedtime, heat escapes our body through the periphery, in particular extremities and skin," said Dr. Lisa Meltzer, associate professor of pediatrics at National Jewish Health in Denver and board-certified sleep behavioral medicine expert.<sup>4</sup> "This is believed to be one factor that contributes to increased itchiness right before bed."

## Can melatonin supplements really help?

Melatonin has been documented in both *in vivo* and *in vitro* studies to help fight free radicals in our bodies and function as a potent anti-inflammatory agent.<sup>5</sup> This means melatonin stimulates a series of antioxidative activities within the body, which can help protect skin integrity and maintain a functional epidermal barrier.<sup>5</sup>

## Since melatonin is a key player in kicking off these anti-inflammatory activities, this is why it's thought to help reduce eczema flare symptoms that may be keeping you up at night.

Melatonin helps regulate our circadian rhythm, which in turn regulates immune function. Levels of proinflammatory cytokines, such as IL-1 $\beta$ , IL-2, TNF- $\alpha$ , IFN- $\gamma$  and IL-6, are increased at night and generally promote sleep.<sup>5</sup> The production of these specific cytokines coupled with cortisol secretion at night are thought to contribute to reducing the urge to itch and disrupting a sleep cycle.

In a 2016 study for melatonin supplementation for children with atopic dermatitis and sleep disturbance, results were evaluated using the Scoring Atopic Dermatitis (SCORAD) index. After melatonin treatment among the 48 children included in the study, the SCORAD index decreased by 9.1 compared with after placebo.<sup>6</sup> The results concluded that melatonin supplementation is a safe and effective way to improve the sleep-onset latency and disease severity in children with atopic dermatitis.<sup>6</sup>

While more research is still needed determine melatonin's proven benefits for people with eczema, it "likely works better at managing active flares, as opposed to preventing flares," said Dr. Fishbein. While melatonin is generally well tried, some common side effects may include nausea, headache, dizziness, or feeling overly tired or groggy. However, long-term sleep deprivation can have more lasting

negative effects on attention, performance, productivity and mood swings, in addition to being associated with higher rates of anxiety, depression and an increased risk for other serious health issues.<sup>1</sup>

## Where can I find melatonin, and how much should I take?

Melatonin is an over-the-counter supplement, available at most drug stores or to order online. There are many different brands and forms of melatonin, or melatonin-containing sleep aids, to choose from. Prices vary depending on quantity and brand, but the most common brands found on sites like Amazon or Walmart typically run for prices ranging between \$7–\$12 per bottle for a 1–3-month supply.

Since it's considered a dietary supplement, melatonin is not as strictly regulated by the FDA. Therefore, it's important to check ingredient lists and look for a tried and trusted brand. You may ask your doctor or pharmacist for a recommendation based on your needs. The key is to ensure you're taking the correct dose: "Melatonin is typically taken every night, about 30 minutes before bedtime with general dosing of 1 mg in infants, 2.5–3 mg in older children and 5 mg in adolescence/adults," said Dr. Fishbein.

## Melatonin and you: Is this the beginning of a beautiful, albeit drowsy, friendship?

While more research is still needed to determine how nightly melatonin supplements can help reduce flares, they've proven to be helpful for many people with eczema who experience sleep disturbances. "Do not be afraid to ask your [healthcare] provider for a referral to a sleep medicine expert. Good sleep is really important for physical, psychologic and immune health," said Dr. Fishbein. If you find yourself lying awake at night, unable to stop scratching, just know you're not alone. Melatonin supplements may be a game changer in improving the quality of your sleep.

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# How Covid-19 Affected My Eczema

By Daniel Boey, NEA Ambassador, and Dr. Peter Lio, Assistant Professor of Dermatology and Pediatrics at Northwestern University's Feinberg School of Medicine

Earlier this year, I became a national statistic.

The day started off like any other. I drove to the bay to walk my dogs along the breezy promenade. Had a relaxed lunch. Washed the sheets and did the laundry. Ordered in finger sandwiches and tea for a mid-afternoon snack.

Then it hit me like a ton of bricks.

The fever came so suddenly, I barely had time to assess the situation. I threw on a jumper and collapsed on the bed, shivering under the duvet. I woke up in time for dinner and to feed the girls, after which I self-administered an antigen rapid test.

There was no denying the double lines on the test kit. I did a second test just in case and the lines were there, staring at me, thick and robust.

"For many inflammatory conditions, including eczema, stress can be a trigger for a flare. Stress comes in many forms, not just psychological. Getting an infection, including a viral infection, can be a huge stress to the immune system and some patients will have a flare, sometimes a very bad one. The good news is that, typically these are fairly short lived and once the stressor subsides, the immune system usually goes back to baseline."

-Dr. Peter Lio

The good thing was, I consoled myself, I had miraculously stopped scratching! I was finally going to get a positively good, uninterrupted, itch-free night's rest.

I woke up the next morning to bloodied sheets. Almost overnight, angry red bumps had erupted all over my body, on my limbs, my scalp, even on the back of my hands and the top of my feet!

It was such a chore to move around, let alone take a shower. I fed the girls, called in my meals and spent the rest of the day in bed.

My well-meaning friends would say things like: "Drink plenty of water," or "coconut juice is good for you" or "take lots of vitamin C." However, my first thoughts were reporting my situation to the Ministry of Health. I was due to take my booster shot in 10 days, which obviously wouldn't work now that I had been infected. And the responsible thing would be to inform the relevant authorities. However, it was the eve of Chinese New Year and everywhere was either closing or closed. And they would remain shut for the next three days.

"It is such an important point that once in the itch-scratch-itch cycle, things often do not 'just go away.' It is a vicious cycle of skin barrier damage, inflammation and a terrible, deep itch that can sometimes be absolutely unrelenting."

-Dr. Peter Lio

The rash did not subside but instead found new places to sprout. It was unlike anything I had ever experienced. The bumps were more pronounced, especially on my hands and feet. And it was so itchy. I took out my strongest cream and moisturized like my life depended on it.

My doggies went to their BFFs for an emergency staycation so that I could concentrate on resting and getting better.

On the first day of the Chinese New Year, the rash started to dry, which meant my skin started to crack from the dryness. The pain was excruciating. It hurt to even move. I started applying cold press extra virgin coconut oil, which I use on my dogs too. It gave minor relief, but my skin was so thirsty it absorbed the oil almost as fast as I applied it.

As the skin dried, it started to flake, from my scalp to my feet. I left bits of skin everywhere I went and had to constantly vacuum. When I woke in the morning, I had to vacuum the sheets and the surrounding floor to get rid of the layer of dried skin that had fallen off. I was terrified that the skin flakes would attract bed mites.

And the itch got worse!

Finally, on the third day of the Chinese New Year, businesses started to open again and I could see a doctor for an official antigen rapid test. He addressed every single one of my problems – the fever, the cough, the discomfort ... but he ignored the eczema. Maybe he didn't know what to do, as he wasn't a specialist, but he waved it off with a dismissive "just moisturize, it will go away."

"It is unfortunate but true that many doctors, even excellent ones, are not well trained in skin issues and sometimes may appear dismissive. I truly believe that for many it is a lack of understanding the impact more severe skin diseases can have. I have found that many non-dermatologists are shocked by the impact skin disease can have on patients. It is work that must continue to be done, the world over."

-Dr. Peter Lio

It did not "go away," but instead the dry skin started to crack and bleed. It didn't help that I would scratch in my sleep, tearing at the itching scabs. This also meant that the eczema could not heal. Logic told me to stop scratching, but the flesh is weaker than the spirit. I cut my nails extra short, I wore long sleeved pajamas and socks, to no avail.

Several days after testing positive, I woke in the middle of the night to some discomfort on my feet. My socks felt like they had shrunk. I removed them to find that my feet and ankles had swelled. And the rash was still bleeding. The next day, my hands and fingers started to swell too. I started to panic and made an emergency appointment to see the doctor. He gave me some steroids which went some way towards managing the breakouts.

I was still positive nine days later and battling the bloody breakouts, the flaky dry skin and swellings of my hands and feet. The itch hadn't subsided, but at least the fever had. And I finally tested negative on the tenth day.

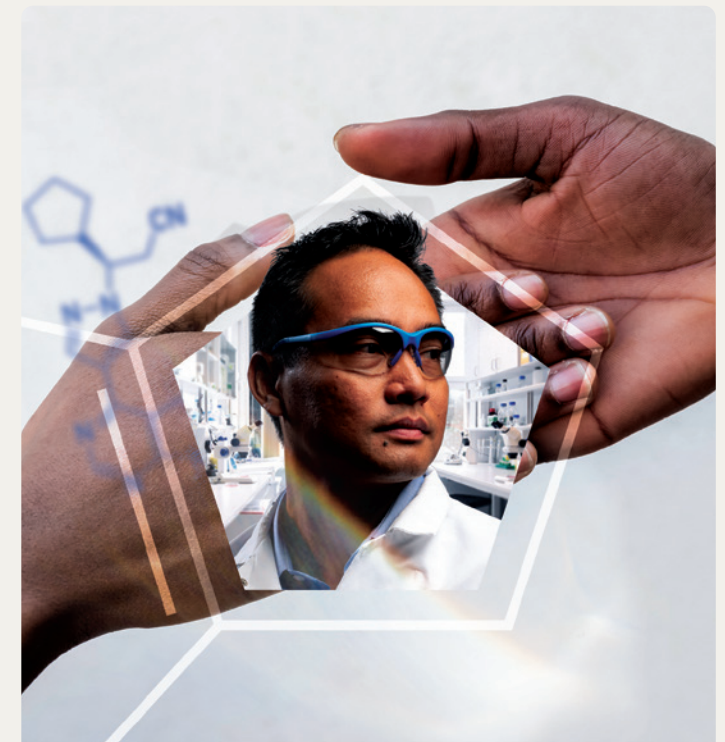
It's been a month since Covid-19 hit me. The fever is long gone, but I am still living with the rash. The eczema is slowly fading, the dryness has subsided and the flaking has stopped; there is less blood on my sheets. But I am still struggling with keeping the condition under control. I've cancelled all my photo shoots, television appearances and filming indefinitely because I don't feel confident appearing in public with my present condition. I have never felt this insecure before.

It seems this severe eczema breakout was triggered because Covid-19 messed with my immunity. I can only hope that the massive breakout has purged my body of toxins and my eczema journey will be easier going forward.

Follow Daniel on Instagram @danielboey for more adventures of his eczema-riddled life.

"One recent survey I saw suggested that something like three out of five adults with eczema are unhappy with their current treatment plan. I think this is extremely concerning and this piece suggests that, weeks later, there are still significant issues with the skin that remain untreated or at least undertreated. It hits me particularly hard because we have more treatments now than ever before, and there is so much exciting research in eczema that I think we really can offer relief to so many patients."

-Dr. Peter Lio



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IT'S ALL RELATIVE

# Are People With Eczema at Greater Risk of Heart Disease?

By Angela Ballard, RN

**To better understand the possible risks of heart disease for people with eczema, we connected with Dr. Anna Ascott with the London School of Hygiene & Tropical Medicine.** As recently as 2018, emerging research in the *British Medical Journal* demonstrated that people with severe atopic dermatitis (AD) had a 40% increased risk of heart attack and atrial fibrillation; 70% greater risk of heart failure; and 20% higher risk of stroke.

In further exploration of this subject, Dr. Ascott and her fellow researchers reviewed 19 different studies on eczema and cardiovascular risks. With this meta-analysis, Ascott and fellow researchers found that risks of cardiovascular disease and certain cardiovascular events increased depending on the seriousness of a person's eczema symptoms. Their results were published in *The Journal of Allergy and Clinical Immunology*. Specifically, the scientists found that severe eczema was associated with increased risk of angina (chest pain caused by inadequate blood to the heart), heart failure, myocardial infarction (heart attack) and cardiovascular-related death.

"In our research," said Ascott, "we found that people with severe atopic eczema were more likely to develop cardiovascular diseases than people with milder forms of atopic eczema. This was also true for people who had atopic eczema that was active more regularly compared to those who only had active atopic eczema some of the time." Ascott



speculated that the reasons for this may be that a person with more severe and active eczema has more inflammation in the body and that increased inflammation increases the chances of developing cardiovascular problems, as is seen with other inflammatory conditions, like rheumatoid arthritis.

If this sounds like a lot to process, don't worry. "The good news," said Ascott, "is that although people with moderate and severe atopic eczema are at higher risk of heart disease, the overall risk is low. When we combined existing studies together, we found that the risk of developing angina, heart attack, heart failure, stroke or cardiovascular death was 15% greater in people with moderate atopic eczema and 32% greater in people with severe atopic eczema, compared to people with mild atopic eczema."

There is not yet data to tell us exactly why or how severe eczema is associated with cardiovascular risks, but there are some theories. As Ascott mentioned, other inflammatory conditions have been linked to cardiovascular disease; people with eczema typically have weaker skin barriers which can lead to more skin infections and, in turn, greater overall inflammation. Another theory is that platelet dysfunction and differences in fibrin and clotting in patients with eczema could be a factor. Ascott noted, too, that certain treatments for eczema could impact cardiovascular risks.

"Oral corticosteroids," she said, "in short courses can be very helpful for patients. But if oral corticosteroids are used long term they have many side effects including increasing blood pressure and

cholesterol, and increasing the risk of diabetes and obesity, all of which lead to cardiovascular diseases."

Given these links between severe eczema and cardiovascular conditions, should we be taking better care of eczema for heart-health reasons? Based on the limited research so far, Ascott is not yet sure.

"This is a really important question," she said. "Some studies in other diseases have looked at what happens if inflammation is reduced with treatments and have found that the likelihood of developing cardiovascular diseases does reduce, but we need to do more research on this topic with atopic eczema."

Of course, when it comes down to it, everyone should be looking after their hearts as well as their skin. According to the CDC, **heart disease is the leading cause of death for men, women and people of most racial and ethnic groups in the United States.**

For anyone looking for more information, we've got heart-healthy tips for people with eczema:

- 1 **Most important: talk to your doctor about your heart health.** If you have severe eczema, eczema that covers a large portion of your body, if your eczema is difficult to manage, or if your eczema flares for extended periods of time, ask your doctor about your heart health and whether there are any additional health risks you should consider.

- 2 **Have your blood pressure checked regularly.** This is likely already a part of your check-ups, but if not, or if you aren't having check-ups, now's the time to get into a routine. If push comes to shove, you can measure your blood pressure at certain pharmacies, as long as you follow up with a doctor about any concerning results. The U.S. Department of Health and Human Services says we should all be getting our blood pressure measured "regularly" after the age of 18. People at higher risk are recommended to have blood pressure taken once a year. What's considered higher risk? You're at increased risk for high blood pressure if you:

- Are overweight or obese;
- Are Black;
- Don't get enough physical activity;
- Drink too much alcohol;
- Smoke;
- Don't eat a healthy diet;
- Have kidney failure, diabetes or heart disease.

- 3 **Monitor your cholesterol.** Some pharmacies can also do cholesterol lab work. Again, please be sure to consult with a healthcare provider about your results. The CDC says that most healthy adults should have their cholesterol measured every four to six years. But if you have severe eczema, you probably want to consider having it reviewed more often. Children and adolescents should have their cholesterol checked at least once between ages 9 and 11 and again between ages 17 and 21.

- 4 **Follow heart-healthy guidelines from the National Heart, Lung and Blood Institute:**
- Know your family's medical history and communicate it to your care providers. Pay special attention to any heart issues or diabetes mentioned by relatives.
  - Eat well, focusing on foods that are low in: saturated fat, added sugar and salt. Eat more high-fiber foods (whole grains, fruits and vegetables) and better fats (like those in olive oil and fish). You can follow this nutritional and dietary advice for eczema and heart health.
  - If at all, drink alcohol only in moderation. This means no more than one drink per day for women and two drinks or fewer per day for men. Avoiding alcohol may also help your eczema with studies showing drinking can make skin conditions worse.
  - Get active with at least 150 mins of moderate-intensity physical activity per week for adults (that's just 21 minutes a day). Do something that increases your heart rate and is enjoyable. Walk, bike, dance, swim, skip, etc.
  - Stay at a healthy body weight. Easier said than done. We know. But by losing even 5% to 10% of your body weight (if you need to) you can help your heart. Talk to your doctor about what's a heart-healthy weight for you.

- Quit smoking and avoid secondhand smoke. If you need help kicking the habit, ask your doctor for advice or visit the CDC's pages on this topic. There are medications, apps and government resources to give you support. Other people in your life still smoke? Ask them to step outside.
- Manage stress. This is great for your heart as well as your skin as we know that stress relief techniques help eczema and dealing with stress can help you to avoid eczema flares.
- Get enough sleep, ideally 7-9 hours per night for adults aged 18 or older.

- 5 **Be aware of the warning signs of heart conditions and get immediate medical help when you need it.** Symptoms of a heart attack or another cardiovascular problem can include:
- Chest pain especially if it spreads to your arm or jaw and doesn't pass quickly;
  - Unexplained nausea, indigestion, or heartburn (particularly in women);
  - Unusual fatigue or general weakness;
  - Shortness of breath;
  - Changes in skin color (gray pallor for light skin tones, more yellowish changes for those with brown skin, or pale palms or interior cheeks for those with dark skin);
  - Coughing or wheezing that doesn't go away or coughing up mucus that is pink or bloody;
  - Swelling or numbness in the lower legs;
  - Irregular heart beat;
  - Feeling lightheaded or dizzy;
  - Sweating for no reason;
  - Unusual snoring (sleep apnea).

Not everyone is cognizant — not yet at least! — that there's a connection between severe eczema and heart health, but now you are. We hope you use this information to advocate for yourself, your loved ones and heart health this month and every month.



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# Original Artwork From Our NEA Community

We asked members of our eczema community to submit original artwork. It didn't necessarily have to deal with eczema, we just wanted to see your creative expression. And boy did we! We're so excited to showcase some of the work here. To submit your work for an upcoming issue, email [editor@nationaleczema.org](mailto:editor@nationaleczema.org).



↑ **This Is Who I Am!**

Ashley Hardy

← **My Skin Barrier Is Not Intact  
But My Integrity Is**

Morgan Banks



↑ **Skin**

Roxane Lamoureux



↑ **Night Eye**

Chiz Okafor



↑ **Blooming**

Cindy Letourneau-Fernandez



↑ **Mom**

Gabriella Vital



# 5 Terms Your Dermatologist Uses That You Might Not Understand

Have you ever left an appointment with your dermatologist feeling confused by all the medical jargon? You are not alone. The language of eczema can be complex, full of precise terms that dermatologists master in their training, but don't always explain to their patients.

To help you gain more confidence at the doctor's office, we asked a board-certified dermatologist, Dr. JiaDe (Jeff) Yu, who works at Massachusetts General Hospital, to explain five medical terms he often uses with his eczema patients.

## Why It's Important

Research has shown that clear communication can improve the quality of doctor-patient relationships and help patients stay on their treatment plans.<sup>1</sup>

Dr. Yu also pointed out that understanding some medical terminology can support patients in keeping up-to-date on the latest developments in the field. He explained, "These terms are often used in the medical literature, on expert websites and in studies looking at medications for the treatment of atopic dermatitis. Knowing them can

enhance the patient's understanding of what's going on in the world of atopic dermatitis from the clinician's perspective."

## 5 Key Terms

### 1 Pruritus (proo-RIE-tus)

If you have eczema, you may not know this term, but you are likely all too familiar with what it describes – itch.

Itch is a major symptom of all seven types of eczema. It can keep people awake at night, trigger or worsen flares and lead to mental health difficulties such as irritability, depression and anxiety.

Recent research into the causes of pruritus may lead to new treatments in the near future. In the meantime, it can be managed in a number of ways, ranging from oatmeal baths to prescription medications.

### 2 Lichenification (lai-ken-uh-fi-KAY-shuhn)

According to Dr. Yu, lichenification "is a telltale sign for the dermatologist that the area has been itchy for a long time, and the patient has been scratching and itching for a long time."

He explained, "It means the skin is thickened, to resemble lichen, due to chronic itching and scratching. The skin lines are accentuated, or deeper and more obvious than normal."

Some people with lichenification may notice the thickened skin appears darker than usual.<sup>2</sup> Sometimes small bumps (also known as papules) may appear.<sup>2</sup>

Lichenification is divided into two categories – primary and secondary.<sup>3</sup> Primary lichenification is driven by chronically itchy patches of skin, usually in one or two areas of the body. This is also called neurodermatitis or lichen simplex chronicus.<sup>3</sup> This condition can be triggered by stress, tight clothing, bug bites, nerve injury or dry skin.

Secondary lichenification is caused by an acute itch resulting from an underlying medical condition such as atopic dermatitis.<sup>3</sup>

Lichenification is treated by ending the itch-scratch cycle and healing the skin. Dermatologists may recommend treatments that can include topical corticosteroids, calcineurin inhibitors and ointments made with salicylic acid to control the itch. Some people have also found that going to counselling to manage anxiety, meditating or using cognitive-behavioral therapies can be useful.

### 3 Excoriation (ik-sko-ree-AY-shun)

An excoriation is a scratch or a wound caused by scratching or picking at the skin.

Although these lesions are relatively superficial, they can become problematic due to infection. "They can be portals of entry for bacteria such as *Staphylococcus aureus* that can infect over 80% of patients with atopic dermatitis," said Dr. Yu.

Some ways to minimize excoriations are keeping your fingernails trimmed, or wearing gloves at times you are most likely to scratch, such as before sleep or while watching TV. Keeping your hands busy by doodling, squeezing a stress ball or using a "fidget" can also be helpful.

### 4 Fissure (FI-shr)

A fissure is a linear crack in the skin. Dr. Yu said they "can occur due to dryness, inflammation and scratching."

He noted that fissures can be painful. They are most common on the hands and feet.

Eczema warrior Sarah Harris shared her experiences with fissures. "My skin morphs into a desert-scape, dry and crackling. Fissures run like deep ravines at the creases of my knuckles, the corners of my lips, even behind my knees."

To heal the fissures on her skin, Harris applies a thick moisturizer, then covers the affected area with cotton gloves, or a bandage. These measures aid in repairing the skin barrier and preventing infection.

### 5 Flexural (FLEK-shur-al)

Flexure means a bend or a curve. Flexural describes areas of the body that bend, like the backs of the knees (popliteal fossa), or elbow creases (antecubital fossa).

Dr. Yu explained that atopic dermatitis flares are common in these areas. Some dermatologists use the term "flexural eczema" interchangeably with "atopic dermatitis."<sup>4</sup>

Flexural flares likely occur because salts from sweat build up in these areas, irritating the skin. Keeping these areas as dry as possible, especially in the summer, can help.

## In Conclusion

Knowing a few medical terms is a good way to improve communication between you and your health care providers. But questions may still arise. Don't hesitate to ask them. Having a clear understanding of your diagnosis and treatment is key to managing your condition successfully.

<sup>1</sup> Derevianchenko N, Lytovska O, Diurba D, Leshchyna I. Impact of medical terminology on patients' comprehension of healthcare. *Georgian Med News*. 2018;(284):159-163. <https://pubmed.ncbi.nlm.nih.gov/30618411/>. Accessed January 17, 2022. <sup>2</sup> Aboobacker S, Harris BW, Limaier F. Lichenification. StatPearls Publishing. Updated May 9, 2021. Accessed January 17, 2022. <https://www.ncbi.nlm.nih.gov/books/NBK537332/>. <sup>3</sup> Fletcher J, Sullivan D. What is lichenification? *Medical News Today*. March 24, 2020. Accessed January 17, 2022. <https://www.medicalnewstoday.com/articles/lichenification?c=1301019978505#symptoms>. <sup>4</sup> Jacob SE, Goldenberg A, Nedorost S, Thyssen JP, Fonacier L, Spiewak R. Flexural eczema versus atopic dermatitis. *Dermatitis*. 2015;26(3):109-15. doi:10.1097/DER.0000000000000102.



# NEA Community Poets Share Their Eczema Haikus

In honor of National Haiku Day, we asked our community to share their poetry. As many of you have so capably demonstrated, a haiku is a poem with three lines, five syllables in the first line, seven syllables in the second line and five syllables in the third line. Enjoy!

Though you scream at me,  
Blistering, hopeless weeping,  
I can't help but shred.  
@puuthulhu

Cool air on wet skin  
Soaking in, dryness returns  
Time to reapply.  
– Dani M

Eczema itches  
Healing with lotions and food  
Goes away, comes back  
@hi\_shureley

Hugging your small frame,  
Rash blooming like spring flowers,  
Why can't it be me  
@azzap

Itchy itchy me  
Flakes and blood spots on my clothes  
There is no relief  
@candylaz

In fear, I hide them  
Crushed by people staring through  
Resisting the itch  
@anonymous

I keep on nail digging  
At night when it is itchy  
Without even realizing  
@anonymous

Nails are cut, of course  
Then how come my skin cut too  
Healing run its course  
@anonymous

My son just can't stop  
Dry itch scratch cycle repeat  
Wish I could end it  
– Jamie Hall

It itches so much  
Painful patches burn all night  
Will it ever end  
– Kristi Calcanas

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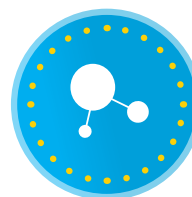


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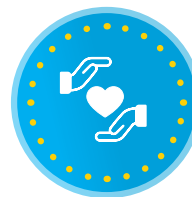
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