



National
Eczema
Association

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NEA Magazine

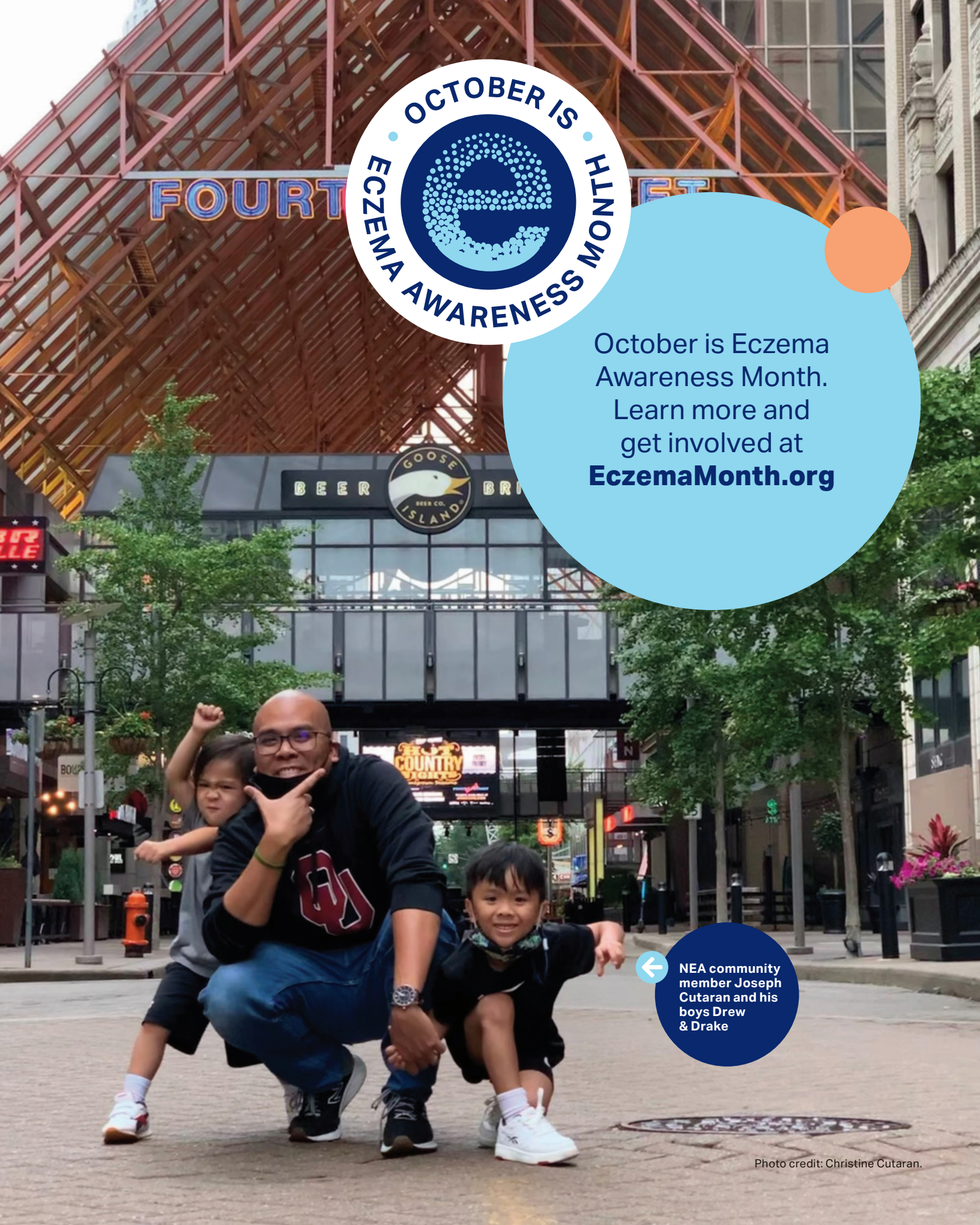
Research, Support and Education for Those Affected by Eczema



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October is Eczema Awareness Month. Learn more and get involved at EczemaMonth.org

← NEA community member Joseph Cutaran and his boys Drew & Drake

Photo credit: Christine Cutaran.

NEA Magazine

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Photo courtesy Patricia Cervini

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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 Julie

Welcome to the fall issue of NEA Magazine!

We were thrilled to see so many of you at Virtual Eczema Expo this year. With hundreds of attendees from around the globe, we were able to say these three powerful words together: WE HEAR YOU. We learned, laughed, cried and — last but not least — we danced our hearts out! We were also deeply moved by your original poetry: check out page 20 for some of the original spoken word odes that members of our community shared at Expo. And mark your calendars for next year's Expo in Seattle, Washington the weekend of July 8-10, 2022.

And we're already into October, which is Eczema Awareness Month (EAM). There are more than 31 million people in the U.S. with eczema — that's one in 10 Americans — and every individual's experience is unique. The symptoms of eczema are complex; the triggers are vastly diverse; and the right treatment varies for every individual. Help us increase awareness of eczema this month by tagging your story on social media with #ThisIsMyEczema and check out EczemaMonth.org for additional tips and resources.

We're also excited to report that the NEA research team has published its second and third articles in an ongoing series about the out-of-pocket costs of eczema. Did you know that nearly 25% of American families report a "significant or devastating" financial burden because of eczema expenses? We've included a visual snapshot on page 28 that illustrates some of the key findings of NEA's own research published in Dermatitis.

Lastly, I'm reaching out to remind you that the end-of-year giving season is right around the corner. For millions of Americans living with or caring for someone with eczema, research signifies our greatest hope for prevention, better treatments and — ultimately — a cure. NEA is poised to dramatically increase its investment in eczema research over the next five years. We are calling on our supporters to invest in this life-changing work.

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

Expo Highlights, New Episodes of Eczema Out Loud and New NEA Research Publications

Virtual Eczema Expo Round-Up

Thanks to everyone who attended Eczema Expo! It was a resounding success thanks to you. With hundreds of attendees from across the United States and around the globe, we were thrilled to see you, hear you and come together as one big NEA community. A few of the highlights included "Now Hear This: The Latest News in Prescription Treatments for Eczema," along with "The Care Conversation" and "TSW: What Now?" Our junior eczema warriors were excited about "Meet My Pets" and "What's Cookin'?" And, last but not least, we were amazed by all the dance skills on display during our Ecz-travaganza dance party: we learned a few awesome dance moves from you! For attendees, the sessions will be accessible through the end of the year at NationalEczema.org/expo-recap.

Overheard at Expo

- "The support here is amazing!"
- "I've been waiting for this all year."
- "There's so much love in this room it's amazing."
- "Hearing everybody's story and realizing you're not the only one: THAT'S why I'm here."
- "By showing up today, you are healing."
- "You are a step above, because you STEP UP."
- "Without eczema, I wouldn't have met my best friends in the whole wide world."
- "I wish I had a community like this when I was a kid"
- "Eczema, my friend, you have been difficult, but you've taught me so much."
- "Please skin, let me rest."
- "Skin of loyalty, skin of royalty."

Eczema Out Loud

If you haven't listened to it yet, be sure to check out the most recent episode of our NEA podcast Eczema Out Loud: Itch-fighting Tips from a Dermatologist Who Has Eczema. Keep an eye out in the weeks ahead for our next episode, too, about caring for infants and eczema. It isn't easy being a parent, and it's even more challenging learning how to care for your infant's eczema. Visit NationalEczema.org/podcast to listen and subscribe!

NEA Research Publications

The NEA Research Team is making waves with two new publications drawing from their work on the hidden out-of-pocket (OOP) costs of living with eczema. Featured in the September e-publication of Dermatitis, the NEA-authored article established a correlation between increased severity of atopic dermatitis (AD) and increased OOP expenses for treatment. The NEA team also published an article in the Archives of Dermatological Research that explores the disproportionately high OOP costs that Black Americans face in managing their AD when compared to non-Black Americans. A big thank you to all NEA community members who complete our surveys. This vital, ground-breaking research is not possible without your engagement — together we WILL make a difference!

NEA QUIZ

Of adult Americans with AD (patients and caregivers), how many report that AD has a "significant or devastating" impact on their personal or family finances?

- A. 1 in 10
- B. 1 in 6
- C. 1 in 4
- D. 1 in 2

See the answer on the bottom of the next page!

This Is Why I Give

My name is Kerry Benjamin and I live in Los Angeles. This is why I give to NEA.

I have battled eczema all my life. The itch is exhausting and frustrating, as well as mentally and physically draining. I've been on Prednisone, topical steroids, and I've had allergy shots. I've suffered through MRSA infections, one of which landed me in the hospital. I became an aesthetician because of my struggle with eczema: I wanted to learn about skin and find ways to help myself and others with their skin.

"I donate to NEA to support research for new treatments and programs that will help kids with eczema feel accepted."

I've had eczema since I was a child, and it made me feel ugly and uncomfortable around my peers. It was really hard on me. I hope that we can find better medicine to control eczema flare ups and to foster a caring community to help us all cope with the anxiety and mental health issues that eczema causes.

For me, the hardest thing about living with eczema is how uncomfortable it is. The burning itchy skin makes me irritated and frustrated. Sleep deprivation caused by eczema is also really hard.

I hope that thanks to my donation and donations from other supporters, researchers will be able to develop better treatments to help people manage their eczema.

NEA Quiz Answer:

C. 1 in 4

A newly published study demonstrated that 24.5% of survey respondents indicated that out-of-pocket (OOP) expenses related to AD had a significant or devastating impact on their personal or family finances, and 40.1% of respondents reported that AD-related OOP expenses had a moderate impact on their finances.

Reference:
Chovatiya, R*; Begolka, WS; Thibau, I; Silverberg, J. Impact and Associations of Atopic Dermatitis Out-of-Pocket Health Care Expenses in the United States. *Dermatitis*: 2021; September 13.



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AMBASSADORS' CORNER

"I Felt Like My Voice Was Finally Being Heard"

Sam Bittner represents the eczema community in evaluation of new eczema treatments

By Steve Nelson



Photo courtesy Sam Bittner

Sam Bittner knows eczema. The 22-year-old college student has lived with severe and often debilitating atopic dermatitis (AD) since she was an infant, and this firsthand experience motivated her to sign on as a NEA Ambassador to help improve the lives of others living with eczema.

On July 23, 2021, Sam served the critical role as the sole patient voice in a public meeting held by the Institute for Clinical and Economic Review (ICER), a final step in the evaluation of the clinical effectiveness and value of new and pending treatments for AD, including JAK Inhibitors and a new biologic. A nonprofit research organization, ICER engages drug manufacturers, patient advocates and healthcare providers to develop recommendations on drug pricing and coverage. ICER's evaluation has no impact on FDA approval.

NEA was invited to participate in the ICER review as a key stakeholder throughout the process, and facilitated Sam's role in the July meeting to share her personal, lifelong experience with AD. From the start, Sam's message was clear: "Every part of my life is affected by this disease," she said, "All I know is that I want to feel better."

With the support of NEA, people who live with eczema are playing a more visible role in the development of new treatments and in the decisions that affect their healthcare. "I was incredibly nervous at first," Sam said. "But as I started telling my story, I noticed how every single person was paying close attention. I felt like my voice, and other patient voices, were finally being heard."

Due to the heterogeneous nature of eczema, the day-to-day lived experience can vary greatly across the patient population; a treatment that might help one person's AD may be ineffective for someone else's symptoms — and possible side effects, according

to Sam, can make a patient feel like "they're constantly picking the lesser of two evils" in choosing a treatment. "An ideal treatment would relieve my inflammation and itch without compromising any other parts of my health," she said.

Conveying the potential impact these new treatments could have on patients' lives, Sam described the negative impact of eczema on her relationships, education, sleep, mental health and career plans. "Most days I feel more like a patient than a person," she said. "I can't even grocery shop without having an escape plan in case my eyelids start to crack and bleed."

For many patients and caregivers, the challenges of eczema are compounded by having few long-term treatment options. The possible future approval of new treatments may provide patients with additional choices, but only if they are accessible in terms of cost and coverage.

"I am hoping that there will be more treatment options that everyone has access to."

~ Sam Bittner

It's critical that patients and caregivers be included in conversations about their care. **If you'd like to claim your seat at the table and be notified of future opportunities, become a NEA Ambassador!**

GET AHEAD OF ECZEMA AND SHOW MORE SKIN

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

Approved for ages 6 and up.

- ▶ Fast itch relief*
- ▶ Not an immunosuppressant
- ▶ Clearer skin that lasts*
- ▶ 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.

TALK TO YOUR ECZEMA SPECIALIST AND GO TO DUPIXENT.COM TO FIND OUT MORE

INDICATION

DUPIXENT is a prescription medicine used to treat people aged 6 years 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” if you are treated with DUPIXENT; are pregnant or plan to become pregnant. It is not known whether DUPIXENT will harm your unborn baby. There is a pregnancy exposure registry for women who take DUPIXENT during pregnancy to collect information about the health of you and your baby. Your healthcare provider can enroll you or you may enroll yourself. To get more information about the registry call 1-877-311-8972 or go to <https://mothertobaby.org/ongoing-study/dupixent/>; 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 (hypersensitivity), including a severe reaction known as anaphylaxis. Stop using DUPIXENT and tell your healthcare provider or get emergency help right away if you get any of the following symptoms: breathing problems, fever, general ill feeling, swollen lymph nodes, swelling of the face, mouth and tongue, hives, itching, fainting, dizziness, feeling lightheaded (low blood pressure), joint pain, or skin rash.

Eye problems. Tell your healthcare provider if you have any new or worsening eye problems, including eye pain or changes in vision.

The most common side effects in patients with atopic dermatitis include injection site reactions, eye and eyelid inflammation, including redness, swelling, and itching,


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, or call 1-800-FDA-1088.

Use DUPIXENT exactly as prescribed. Your healthcare provider will tell you how much DUPIXENT to inject and how often to inject it. DUPIXENT is an injection given under the skin (subcutaneous injection). If your healthcare provider decides that you or a caregiver can give DUPIXENT injections, you or your caregiver

should receive training on the right way to prepare and inject DUPIXENT. **Do not** try to inject DUPIXENT until you have been shown the right way by your healthcare provider. In children 12 years of age and older, it is recommended that DUPIXENT be administered by or under supervision of an adult. In children younger than 12 years of age, DUPIXENT should be given by a caregiver.


Please see Brief Summary on next page.

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CALL 1-844-DUPIXENT (1-844-387-4936)

Brief Summary of Important Patient Information about DUPIXENT® (dupilumab) Rx Only (DU-pix'-ent) injection, for subcutaneous use

What is DUPIXENT?

- DUPIXENT is a prescription medicine used:
 - to treat people aged 6 years 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.
- DUPIXENT works by blocking two proteins that contribute to a type of inflammation that plays a major role in atopic dermatitis.
- It is not known if DUPIXENT is safe and effective in children with atopic dermatitis under 6 years of age.

Who should not use DUPIXENT?

Do not use DUPIXENT if you are allergic to dupilumab or to any of the ingredients in DUPIXENT. See the end of this summary of information for a complete list of ingredients in DUPIXENT.

What should I tell my healthcare provider before using 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” if you are treated with DUPIXENT.
- are pregnant or plan to become pregnant. It is not known whether DUPIXENT will harm your unborn baby.
 - **Pregnancy Exposure Registry.** There is a pregnancy exposure registry for women who take DUPIXENT during pregnancy. The purpose of this registry is to collect information about the health of you and your baby. Your healthcare provider can enroll you in this registry. You may also enroll yourself or get more information about the registry by calling 1 877 311-8972 or going 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 of 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
- 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.

How should I use DUPIXENT?

- **See the detailed “Instructions for Use” that comes with DUPIXENT for information on how to prepare and inject DUPIXENT and how to properly store and throw away (dispose of) used DUPIXENT pre-filled syringes and pre-filled pens.**
- Use DUPIXENT exactly as prescribed by your healthcare provider.
- Your healthcare provider will tell you how much DUPIXENT to inject and how often to inject it.
- DUPIXENT comes as a single-dose pre-filled syringe with needle shield or as a pre-filled pen.
- DUPIXENT is given as an injection under the skin (subcutaneous injection).
- If your healthcare provider decides that you or a caregiver can give the injections of DUPIXENT, you or your caregiver should receive training on the right way to prepare and inject DUPIXENT. **Do not** try to inject DUPIXENT until you have been shown the right way by your healthcare provider. In children 12 years of age and older, it is recommended that DUPIXENT be administered by or under supervision of an adult. In children younger than 12 years of age, DUPIXENT should be given by a caregiver.

- **If your dose schedule is every other week and you miss a dose of DUPIXENT:** Give the DUPIXENT injection within 7 days from the missed dose, then continue with your original schedule. If the missed dose is not given within 7 days, wait until the next scheduled dose to give your DUPIXENT injection.
- **If your dose schedule is every 4 weeks and you miss a dose of DUPIXENT:** Give the DUPIXENT injection within 7 days from the missed dose, then continue with your original schedule. If the missed dose is not given within 7 days, start a new every 4 week dose schedule from the time you remember to take your DUPIXENT injection.
- If you inject more DUPIXENT than prescribed, call your healthcare provider right away.
- Your healthcare provider may prescribe other medicines to use with DUPIXENT. Use the other prescribed medicines exactly as your healthcare provider tells you to.

What are the possible side effects of DUPIXENT?

DUPIXENT can cause serious side effects, including:

- **Allergic reactions (hypersensitivity), including a severe reaction known as anaphylaxis.** Stop using DUPIXENT and tell your healthcare provider or get emergency help right away if you get any of the following symptoms: breathing problems, fever, general ill feeling, swollen lymph nodes, swelling of the face, mouth and tongue, hives, itching, fainting, dizziness, feeling lightheaded (low blood pressure), joint pain, or skin rash.
- **Eye problems.** Tell your healthcare provider if you have any new or worsening eye problems, including eye pain or changes in vision.

The most common side effects of DUPIXENT in patients with atopic dermatitis include:

injection site reactions, eye and eyelid inflammation, including redness, swelling and itching, and cold sores in your mouth or on your lips. The following additional side effects have been reported with DUPIXENT: facial rash or redness. Tell your healthcare provider if you have any side effect that bothers you or that does not go away. These are not all of the possible side effects of DUPIXENT. Call your doctor for medical advice about side effects. You may report side effects to FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

General information about the safe and effective use of DUPIXENT.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use DUPIXENT for a condition for which it was not prescribed. Do not give DUPIXENT to other people, even if they have the same symptoms that you have. It may harm them. This is a brief summary of the most important information about DUPIXENT for this use. If you would like more information, talk with your healthcare provider. You can ask your pharmacist or healthcare provider for more information about DUPIXENT that is written for healthcare professionals. For more information about DUPIXENT, go to www.DUPIXENT.com or call 1-844-DUPIXENT (1-844-387-4936)

What are the ingredients in DUPIXENT?

Active ingredient: dupilumab

Inactive ingredients: L-arginine hydrochloride, L-histidine, polysorbate 80, sodium acetate, sucrose, and water for injection

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Issue Date: January 2021

DUP.21.03.0281

RESEARCH

IT'S NOT ITCH: IT'S PAIN!

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

NEA QUIZ

What percentage of adult Americans with AD report experiencing pain with their eczema?

A. 20% B. 45% C. 61% D. 82%

See the answer on the bottom of the next page!

Atopic dermatitis (AD) is well known for being an inflammatory disease associated with a reduced skin barrier and the greatest burdensome symptom, itch. However, physicians like Dr. Johnathan Silverberg, PhD, MPH at George Washington University School of Medicine and Health Sciences paid attention when patients were describing their skin symptoms and heard words such as, “soreness, burning, stinging, painful, tingling, pricking, throbbing, biting and crawling sensation.” He realized patients were describing pain, not itch. To date, very little research has been done on the processes underlying skin pain in AD.

PAIN AND ITCH: TWO SIDES OF A COIN IN ATOPIC DERMATITIS

Dr. Silverberg said, “I think part of why it has taken so long for research to start focusing on pain in AD stems from our understanding of the counter-effects of pain on itch.” Typically, in healthy skin, stimuli that cause pain (such as scratching) temporarily suppress itch.¹ Dr. Silverberg said, “The field had assumed this to be true in AD as well, but it turns out to be far more complicated. Also, the pain experience is

quite mixed in AD with patients reporting pain resulting from inflamed skin, scratching, fissures (cracks and wounds) and intolerance to skin exposure to irritants. This complexity has made pain more elusive for clinicians and even patients to appreciate.”

THE BURDEN AND VARIED PRESENTATION OF SKIN PAIN IN AD

A key, but fundamental question that needed to be addressed in researching skin pain in AD was how many people with AD actually experience pain? In a recent study of 305 adolescent and adult patients with AD, 42.7% reported skin pain associated with their disease, and many reported that their pain was associated with their itch, with scratching, or with both.² Another study found that more than half of adult patients with AD reported skin pain and rated their pain a six out of 10 on a pain scale.³ In a third study of 602 adults with AD, 61% of patients reported experiencing skin pain with one-third experiencing pain once a week and 5% experiencing pain daily. In this study, pain intensity reached as high as seven out of 10.⁴

Experiencing moderate-to-severe skin pain also correlated with reduced quality of life, poor sleep, mental health issues, and worse overall AD symptoms.² Importantly, the researchers noted that for some patients skin pain did not associate with scratching or with skin wounds (e.g. visible scratch marks or skin cracks). Patients whose pain did not correlate with itch or evidence of scratching in this study used words to describe their pain that were indicative of **neuropathic pain** indicating possible nerve damage not associated with scratching.² A follow-up investigation looking at itch and pain severity in adult AD patients over a period of four years showed that skin pain did not always correlate with itch and scratching over time.⁵

“Patients with pain secondary to scratching report more soreness, whereas those with pain secondary to inflamed skin tend to report more burning and stinging.”

~ Dr. Silverberg

Some studies have looked at location of skin pain associated with AD; the results indicate that patient-reported pain seems to be worse on the palms, soles, and chest.^{6,7} Dr. Silverberg said, “AD patients with fissures (cracks or wounds) present on the hands and feet can experience excruciating pain.” In results from a study of 103 AD patients (age 5 years and older) worldwide, 78% reported pain together with itch, with the greatest degree of pain on the hands, around the mouth, and on the toes, which are also areas of the body with the highest number of sensory nerves.⁸ Buttocks, feet, legs, neck, fingers and forearms also were described as painful. Red, cracked, dry skin was most frequently described as “burning” and “stinging”.⁸ Tightness and tenderness were also used to describe pain in these areas. Pain seemed to be aggravated by sweat, warm temperatures, emotional stress, exposure to hot water, rubbing and wearing wool or synthetic clothing. Sometimes use of moisturizer or topical medication actually made pain worse.⁸

NEA Quiz Answer:

C. 61%

Skin pain is a newly appreciated symptom of AD, with 61% of affected adults reporting pain; 33% experienced pain at least once a week; and 5.2% reported daily pain.

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MECHANISMS OF PAIN IN AD

Studies to understand the science underlying pain in AD are in their infancy. Dr. Silverberg said, “We need mechanistic studies to understand how pain co-occurs with itch specifically in AD.” It has been suggested that a long-lasting inflammatory response from chronic AD lesions may sensitize the peripheral (nerves in the skin) and central (nerves in the spine leading to the brain) nervous system, which increases patients’ experience of pain.³

It is currently unknown whether the same nerves that convey the sensation of itch to the spine and up to the brain also act in the signaling of pain.⁹ Dr. Ethan Lerner, PhD, of Massachusetts General Hospital said, “When people look at skin sensation, very rarely is it a pure itch or a pure pain. Different patients will have more of one than the other. The brain might be processing some of the same information differently with different signaling pathways involved.”

As stated above, itching in healthy skin leads to scratching behavior which can result in pain that temporarily reduces the experience of itch. Studies of mice and rats have shown that spinal nerves receive pain input from peripheral nerve fibers (such as fibers reaching the dermis of the skin). Signals are then sent back to suppress the feeling of itch and scratching behavior.⁹ In AD, however, it seems that this neural process does not work properly. Studies are needed to understand the sequence of events — is it itch, scratching and then pain? Or is the pain associated with AD independent of itch? Dr. Gil Yosipovitch at the University of Miami said, “It is clear that there is a component of pain in eczema that is related to inflammation and nerve sensitization that usually is accompanied by itch but can exist on its own.” He suggests psychosocial studies to help understand if patients experiencing pain derive less pleasure from scratching behavior than those not experiencing pain. These kinds of studies may inform how best to treat pain versus itch in AD because the treatment of pain in some cases may actually make itch worse.⁹

CURRENT MANAGEMENT OF SKIN PAIN IN AD

Most studies to date have not looked at how AD therapeutics impact skin pain. Dr. Silverberg said, “For now, it seems that the best approach is to treat the underlying inflammation and itch, which appears to secondarily reduce skin pain as well. We need studies specifically examining the optimal approaches to reducing skin pain in AD.”

For example, researchers have recently examined data from the dupilumab clinical trials (five separate clinical trials in which patients received placebo or dupilumab 300 mg every two weeks or once weekly with and without topical corticosteroids) and found that dupilumab reduced pain and discomfort starting early in treatment and lasting throughout the treatment.¹⁰ One of the newer oral JAK inhibitors pending FDA approval, baricitinib, was recently studied for its ability to reduce skin pain associated with AD in three Phase III clinical trials. This drug reduced skin pain severity by day two after initiating treatment.¹¹ Targeting pain receptors by using gamma aminobutyric acid (GABA)-targeting drugs or antidepressants

may also alleviate pain.¹² In addition to these newer therapies, one study found that cool temperatures, use of moisturizers, reducing emotional stress, getting good sleep, exposing skin to a cool, wet towel, and topical steroid use relieved some of the burden of pain.⁷

Dr. Yosipovitch said, “Dermatologists need to be aware that pain sensations are part of the eczema and not unrelated. It is important to ask our patients about these sensations.” Patients also need to share if they are experiencing pain, as it has been reported that while the skin pain of AD can be intense, patients do not use pain medication more than those without AD.⁶ As patients think about their skin pain both with and without itching/scratching more information will be conveyed to physicians about how AD pain is experienced. Increased awareness of this burdensome symptom, and evaluation of pain endpoints in clinical trials for new AD therapies will go a long way toward better understanding and treating the pain associated with AD.

TAKE-HOME POINTS:

- Pain is a distinct burden in AD, separate from itch, and is a newer area of research.
- Available data suggests that nerves within the skin and the immune system play a role in skin pain in AD, but much more research is needed to better understand the science and how this relates to the patient experience.
- There are some treatments that can help with skin pain, but additional investigation is needed to understand how current and future treatments can alleviate this burdensome symptom.

GLOSSARY

Neuropathic Pain — One of the most intense types of chronic pain which is caused by damaged nerves or a problem with the nervous system. This kind of pain is often described as sharp, stinging, or burning.

Neurogenic Pain — The nerves involved in pain are undamaged.

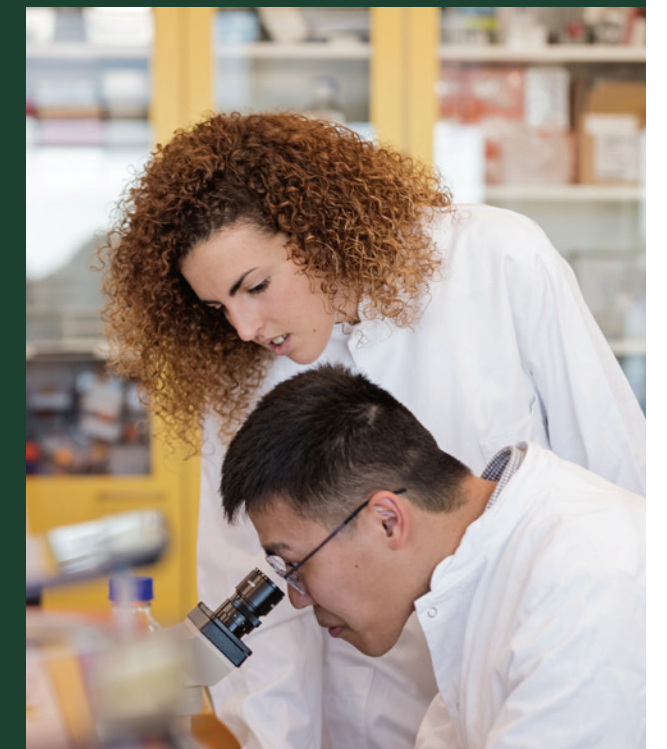
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A Manifesto for Our Community

1
WE BELIEVE

people with eczema are the experts in what it's like to live with eczema.

2
WE BELIEVE

in the chronic, serious and sometimes debilitating nature of eczema and commit to changing public perception of it as "just a rash."

3
WE BELIEVE

the true experience of eczema is not well enough understood by the people who make decisions about patients' health.

4
WE BELIEVE

there is no singular patient voice and that the experience of eczema — the symptoms, triggers, burden, treatment, etc. — is unique for each of the 31 million Americans who live with it.

5
WE BELIEVE

that your voice should be heard at every point where decisions are being made that will affect your care and your access to treatment.

6
WE BELIEVE

that people with eczema should have a seat at the table with healthcare providers, drug manufacturers, legislators and other key stakeholders.

7
WE BELIEVE

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GET THE FACTS

Could Cryotherapy Help My Eczema?

By Steve Nelson

Cryotherapy is everywhere these days. LeBron James does it. So does Serena Williams. But it's not just for celebrity athletes anymore.

NEA Ambassador Patricia Cervini uses cryotherapy every week to manage her eczema. NEA Board Member Lynell Doyle said her son Bryson was finally able to get a good night's sleep after his own cryotherapy experience during the worst of his summer flaring. Healthcare providers around the country have started prescribing cryotherapy to treat a variety of medical conditions including arthritis, chronic pain and even prostate cancer. With more cryotherapy centers popping up every week, people with eczema have started asking questions about whether this new therapy could help their symptoms.

But how does it really work? Is it worth the cost? And could it be dangerous?

What is cryotherapy and how does it work?

Cryotherapy, or "cold therapy," is the process of cooling the surface of your skin for two to four minutes in order to constrict the body's blood vessels and decrease internal inflammation. The procedure takes place in a metal cooling chamber that encircles your whole body except for your head. Liquid nitrogen then cools the air in the chamber down to negative 200 degrees Fahrenheit (or colder) while you stand and count down the seconds until your time is up.

In response to the extreme temperature, your brain activates your circulatory system into overdrive. Your blood flow increases and you experience a rush of serotonin and endorphins. Clinics usually provide gloves and foot-coverings to prevent frostbite on your outermost appendages. And once it's over, you step out of the tank, get dressed, and go about your day. There's very little time needed to "warm up" once it's over. The whole process takes less than 30 minutes.

People who have tried cryotherapy report a wide variety of benefits ranging from pain relief, help with weight loss, prevention of migraines and decreased symptoms of anxiety and depression.¹

Could cryotherapy possibly help my eczema?

The short answer is yes, but proceed with caution. Dr. Gil Yosipovitch chairs the Department of Dermatology at Miami University and said that "there are some patients with atopic dermatitis who report that their eczema improves with extreme cold." Since eczema is not a 'one size fits all' condition, it's difficult to predict how an individual might respond to a novel form of treatment like cryotherapy: for one person, a scorching hot shower may sound soothing for their skin, whereas another person with eczema may find the very opposite appealing — an ice cold bath. Dr. Yosipovitch alluded to as much: "There are patients with eczema who report that their skin improves significantly with cold showers," she said. "And these would be the perfect candidates to try cold therapy treatment."

Patricia Cervini lives with moderate to severe eczema and uses cryotherapy multiple times a week. "In my experience with having eczema," she said, "cryotherapy definitely helped with both the itch and pain." Patricia used the words "immediate relief" to describe the effect of cryotherapy on some of her most persistent flares. For her, the only negative was the cost. "It would be a dream come true if health insurance covered cryotherapy."

Lynell Doyle brought her teenage son Bryson to a cryotherapy center during a summer when he was experiencing relentless flares. "The first time he got it," she said, "he was able to sleep through the night for the first time in months." Lynell articulated one of the challenges of cryotherapy: it's unclear how or why exactly it works. "I did not feel that it directly reduced his eczema," she said, "but it made him comfortable, reduced his pain and reduced his need to itch his skin, and all of that helped his skin heal. Therefore, maybe indirectly, the cryotherapy did help his eczema."



Photo courtesy Patricia Cervini

Dr. Brian Kim is the co-director of the Center for the Study of Itch and Sensory Disorders at Washington University School of Medicine in St. Louis, Missouri. He pointed out that there are reports of cryotherapy helping people with eczema but no "rigorous, randomized controlled trials." He added that "there's reason to believe cooling therapy is calming to the nerves and also anti-inflammatory," while advising caution about considering cryotherapy because "the mechanism of action is not clear" and that conventional cryotherapy remains somewhat imprecise.

For people who flare in specific locations, as opposed to their entire body, there's also the option of having targeted cryotherapy with a wand; this is an alternative to the full-body chamber method. Patricia Cervini explained how and why the cryo-wand was the right choice for her. "Dupixent had healed the eczema flares on my body," she said, "but I was still struggling with flares around one eye and my eyebrows. I tried a cryo facial, which involves administering the cryo wand around my face. It only took twelve minutes, and it helped immediately."

Children under the age of 12 are not allowed to use the full body cryo chamber, so Lynell had tried the localized treatment for her son Bryson first. "He was just a kid and he was in such anguish," she said. "So we did it three times a week for a span of four weeks, and it cost \$125 per week. I think it's worth it to give it a try, especially during an intense flare, but you need to be comfortable with the therapist and have a candid conversation about your goals for the therapy."

What are the risks of trying cryotherapy for my eczema?

Before you consider cryotherapy, it's worth educating yourself about the potential risks. Dr. Yosipovitch pointed out that "extreme cold can cause significant dry cracked skin, blisters and even frostbite in the fingers or toes." Dr. Kim added that uncontrolled cryotherapy could lead to "dyspigmentation and scarring." Because of the risks, both Lynell and Patricia articulated how important it is to work with a

GET THE FACTS

trusted facility, where a cryo-therapist can monitor your health and level of comfort throughout the entire experience. And even if you don't experience any negative physical consequences, it's important to remember how much this untested therapy costs. With the average cost per session ranging from \$70 to \$120, it can add up quickly.

Is there any research about cryotherapy and eczema?

Dr. Yosipovitch mentioned a small 2008 Finland study published in *JAMA Dermatology* that explored the effect of cryotherapy on people with eczema in comparison to phototherapy. The study found that cryotherapy "clearly has a steroid-sparing effect with additional statistically and clinically significant improvements in pruritus and sleep disturbances."¹ The researchers observed that some participants continued "improving even after the treatment period" and suggested that future studies should analyze a higher number of treatment sessions over an extended period of time. With such a small sample size, too (11 out of 18 patients completed the treatment period), additional studies are needed.

More recently, the *Journal of Cosmetic Dermatology* published the results of a study whose data "suggest that a novel cryotherapy device may improve itch in patients with mild-to-moderate atopic dermatitis."² The study's sample size only included 28 patients, and of those only 12 completed all of their follow up visits. More than half of the participants reported "poor satisfaction," whereas a small group of patients noted "substantial improvement." This may reinforce Dr. Yosipovitch's observation that there exists a subset of people with eczema who improve with cold water and therefore could also potentially see improvements with cryotherapy. For people whose eczema is aggravated by cold temperatures, Dr. Yosipovitch said: "I would recommend they stay away from this therapy."

People with Eczema Know Their Own Bodies Best

If you live with eczema, you probably already know how your skin would respond to a blast of icy cold air. Before trying cryotherapy, be sure to schedule an appointment with a healthcare provider who you trust, who understands your eczema, and talk through the pros and cons. If, like Lynell's son Bryson, the cryotherapy may bring you a good night's sleep during the worst of your flaring, it may be worth considering.



Photo courtesy Lynell Doyle

If you live with eczema, you probably already know how your skin would respond to a blast of icy cold air. Before trying cryotherapy, be sure to schedule an appointment with a healthcare provider who you trust, who understands your eczema, and talk through the pros and cons.

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PRODUCT OVERVIEW

Retinol is an Anti-Aging Favorite — But Will it Trigger Your Eczema?

By Angela Ballard, RN



Retinol and retinoids, whether in creams, lotions, or gels, are widely used in over-the-counter and prescription skin products. They're also touted for many tantalizing benefits. Indeed, it seems that this family of ingredients can almost do it all: from fighting acne, fine lines, wrinkles, sun damage, uneven pigmentation, to boosting collagen and fostering a healthy "glow."

But there's a catch, especially for people with eczema.

Retinol and retinoids are part of the same class of chemical compounds derived from vitamin A, a key nutrient for boosting cell turnover and, in turn, helping to whisk away dead skin cells, clogged pores and dull skin. Unfortunately, however, retinol and retinoid products can also be irritating if used too frequently or if a formulation is too strong for your skin.

So if you experience eczema and are already prone to skin irritation, is retinol an option? And what should you expect? We asked Dr. Raj Chovatiya, assistant professor of dermatology at the Northwestern University Feinberg School of Medicine in Chicago to weigh in.

"Topical retinoids help the regulation of cell turnover, protein production and inflammation," Chovatiya explained. "This is why

retinol can be very helpful for anyone looking to treat acne or minimize wrinkles. However, several side effects often occur during the first several weeks of therapy, including skin irritation, scaling, redness, pain, burning, and itching." Chovatiya added: "These symptoms are quite familiar to people with eczema! Unsurprisingly, these side effects tend to be more pronounced in individuals with baseline sensitive skin and eczema."

Dr. Chovatiya generally recommends that patients with eczema avoid retinoids, or at the very least, use them only with extreme caution.

"If someone with eczema was interested in trying out a retinoid for the treatment of photoaging or mild acne," Chovatiya said, "I would first recommend having a discussion with a dermatology healthcare provider to thoroughly review potential benefits and risks."

Still wondering if a retinoid might be worth it? Chovatiya and other experts offer the following tips:

- 1 Work closely with your healthcare provider to design a safe, effective and feasible skin care regimen to help tackle whatever your skin care concerns might be — eczema, acne, wrinkles, uneven pigmentation or any combination of these. "I encourage shared decision making between patients and dermatology healthcare providers," said Chovatiya. "Care plans are different for every person living with eczema."
- 2 Choose milder versions. "Retinols are a better initial choice compared to prescription-strength retinoids," Chovatiya said. "Because they are lower in potency, they tend to have milder potential side effects."
- 3 Opt for a retinol product that's also a moisturizer, such as a cream as opposed to a gel.
- 4 Start "low and slow" by applying, for example, a pea-sized amount of your retinol product only one or two days per week. If irritation doesn't occur, and as your skin becomes more adapted to the retinol, it may be possible to gradually ramp up how much and how frequently you apply.
- 5 Know what's "acceptable" irritation when starting a retinol and what's not. Mild symptoms like drier-than-usual skin, light peeling and sun sensitivity can likely be tolerated and "pushed through" while your skin adjusts. Not normal? Active, intense flaking, redness and burning. If you experience these symptoms, halt your retinol use or greatly reduce it. Consult your doctor if irritation persists or worsens.
- 6 As always, emollients, appropriate bathing, and trigger avoidance are the foundation of eczema therapy, and that shouldn't change when using retinol. In fact, Chovatiya encourages his patients to be extra diligent about moisturizer used after applying retinols and throughout the day.
- 7 Be patient. According to experts at Harvard Medical School, retinoids can: reduce fine lines and wrinkles by increasing collagen production, stimulate the formation of new blood vessels in the skin for improved "glow," fade age spots, block acne-related inflammation and soften rough patches. But it might take three to six months of regular use before such improvements are visible and best results can take up to 12 months to appear.
- 8 Remember the importance of prevention. While optimal moisturization and sun protection are always very important aspects of eczema care, these habits are also helpful in preventing many signs of skin aging — hopefully lessening desire for retinoids in the first place!

If you think your skin is too sensitive for retinol, or if you've tried retinol and it wasn't pretty, don't worry. There are other anti-aging ingredients you can try.

"One option," Chovatiya said, "for those who cannot tolerate retinol, are antioxidants like vitamin C and E. This class of products can help to prevent fine lines and pigmentary changes by neutralizing free radicals in the skin."

Another antioxidant option for sensitive skin might be bakuchiol, from the seeds and leaves of the Indian babchi plant. A study published in the British Journal of Dermatology showed that bakuchiol was comparable to retinol in its ability to improve photoaging but with less skin irritation. Another study found that bakuchiol functioned similarly to retinol with twice-daily application for 12 weeks resulting in improvement in lines and wrinkles, pigmentation, elasticity, firmness and photo damage.

One more choice: Choose to admire the lines of distinction on your face as a testament to a life well lived. As Mark Twain said, "Wrinkles should merely indicate where smiles have been."



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Original Poems from Our Community



Letter to My Eczema

By Charnaé Sanders

Life with you has been rough, literally
Instead of smooth sailing,
You stormed into my life bringing in waves of discomfort, dis-ease,
and distrust
Making me feel as if I couldn't rely on my own body, my first home, to feel safe
Because I felt violated
As if the shelter of my skin was invaded
Because I had to tolerate...you

Unlike a friend, you didn't bring joy and empathy
You were a foe that first introduced me to embarrassment and insecurity
Leaving me with dry and irritated skin that was uncontrollably itchy

And every time I scratched,
I secretly prayed that I could scratch you away
So, I would no longer have to suffer from the pain
But even as my body grew older,
Still, you remained

Some seasons, you'd take a backseat
Other times, you'd take center stage
Acting up and taking a bow on my best and worst days

And, oh when you'd flare,
Whew! Talk about pain.

For years, you've haunted me
And I resented you for it
Asking God, what did I do to deserve this?

But over time, I've grown to realize
Maybe, our introduction to one another wasn't a mistake
Maybe it was fate or God's way
Of helping me to see myself more clearly

Teaching me about patience
And the principles of proper moisturization
And listening to my skin instead of covering it

Because I don't have to hide from the truth
That you don't define me or diminish my existence
Just because I have to walk out this journey called life with you

My skin can still glow and I can live freely and abundantly
Without feeling like I have to shrink because you cover me
Instead of looking at you as my enemy,
You've become the part of me that I just have to work on loving a little
bit harder

Because I'm realizing that my healing doesn't just come from the
ointments or the creams,
But from loving myself and seeing myself more clearly
As someone who is still normal and still worthy

So, what if I didn't do anything wrong to deserve you, maybe you chose me
Because you knew I'd become a warrior
Who was strong enough to withstand the rough and great times,
And everything in between

My Shadow

By Megan F.

Since birth, I've had my dry, flaking, irritated, red, oozing, itchy and
crusty partner in crime. No matter where I go, she's always there.
Whatever I do in any situation, whether I'm alone or with family or
friends, or at work... she's there. Sometimes she slows me down,
sometimes I can beat her. And sometimes she makes me forget,
"why did I walk into this room?"

Sometimes she'll just stop me from being able to get out
of bed and she'll cancel my plans, regardless if I've paid
for them or not. However, with proper reinforcement, I can
mostly keep her at bay. And while there are days, I may
mostly have the control, she's always whispering in my ear...
so I'll keep wondering when she'll make her next appearance.
But overtime these many years, I've embraced her during this
lifelong dance, my constant companion. So, I will continue to
learn from her and will do so for the rest of my days.



Royalty Skin

By Raelle Brown

You are royal.
You fight. You fail. You win again.
You are a mighty warrior.
With every warrior comes a proper crowning, and royalty you are.

Nobody else may see beyond the scar
but you've come so far!
When others ask "what's that?!"
Or stare with shameful eyes, or maybe even cause you to cry.
Remember everyday that You FLY. 🦋
because your style comes from the spirit within.

It takes a level of status, fortitude and class to take up this STANCE.
The details, the consciousness of body, mind and soul.
It all takes a toll... but you never fold.

You are royal. Your skin is a royalty novel.
Not only a burden, but a sign to be certain ...
that you are as special as the skies above.
Really you're simply a step-above ...
because you show up still full of love,
even when others might give you a shove.

Kick you while you're down, but you'll never frown
because you have skin of royalty.
Skin of Loyalty
That always finds its way through the unsurity.
It is a joy to be a part of this royal skin family.



Dear Zema

By Harry Do

Dear Zema this is Harry checking in on ya
I've been rollin on the deep end
Thought that I could lean on ya
Our relations took a few turns
Took a few Burns
Universe is going crazy daily
Haven't you heard

Face is orange like a Georgia peach
(Be)fore you flare up can you come and talk to me (x2)

Life is getting flaky
I've been drowning in the fire
Begging can you save me



Lost and Found

By Victoria Li

Lost. Lost in a field of grass. Lost not knowing what to do. Putting
every bit of pain and agony in a bottle and hoped it would disappear.

Run. She tried to run away from her problems, but they always seem
to follow her behind. Until one day she stopped running. Someone
was there to pull her out. Listened to her, talked to her.

Thank you.

Why? Because she knew how it felt. To be locked up in a cell like she
could not move, like she could not breathe.

She dug.

Without knowing that she was digging her own grave. She would have
fallen into that grave because she could not take it anymore.

Once, the little girl, so full of happiness and joy, was beating herself
over something unimaginable.

Perfection.

That ugly word, disgusting and throat slitting, carved a hole in her
soul. Because she forced herself to. She surrendered her command,

and Perfection took over herself. Perfection turned her life into a
living hell. Living in fear, pain, and misery.

All around her things seemed to move faster, faster faster faster.
Excessive weight tugged on her shoulders, bricks stacked on top and
sank down below the horizon into the underworld. In slow motion,
human beings walked like crisp air has hit them hard. As she fell down
the dark tunnel, the gloominess started to dissolve, when she met a
rabbit who seemed to be the only one in a rush. The kind rabbit, soft
and white, helped her find her way around and convinced her to use
her vocal chords.

Today, her void has not been filled but it is definitely stronger than
what it was before. She still has to fill the rest with words. Kind words.
Kind words that will build her walls up--not down. Kind words from
her friends, family, and teachers. Kind words that she so longed to
capture but never could because she was lost.

She was once a girl who lost her way in a map. Once lost in a field of
grass. Once lost not knowing what to do. Once putting every bit of
pain and agony in a bottle, hoping that they would disappear.

In the past she was a missing person. Today she has been found.



Transition

By Ruth-Marie F. Chambers

Misery emblazoned her heart
Like a scarred drunken sailor
Who spiraled into a cyclonic wind
That shadows breath at daybreak
On the doorstep of autumn
Perched atop meditational skin
Awakened from the scratch and itch
That bleeds onto the thin surface
And cries mercy to patient souls.

Limp and listless from cursed dreams
Her masquerade sifts through
Pain-drenched souls and shackled minds
As the pulse of incoherence tap dances
Down darken corridors with steel doors
Locked in bitter blue conformity and pretension
Through pain drenched scratch, itch
Panoramic patchwork
Ablaze with bruised camouflaged skin.

When morning angles its reach through an opening
Slight enough to caress ragged nerves
From a resident intruder poised to torment
Rather than release the twisted hand of fate,
A stranger with credentials clenched against her breast
Beckons, "Will you sit with me? I need some company."



MY JOURNEY

Cynthea Corfah

I was always drawn to the rich culture of New Orleans. I felt like it was a place where I could be myself, wear what I wanted, dance how I wanted and feel free. Turns out, I was right: I fall more in love with New Orleans every day! Unfortunately, Louisiana's humid air and hot sun hasn't helped my eczema at all.

And this is hard for me because I love the beauty in New Orleans. I love the architecture, the parks, the brightly colored homes, the food and all of the friendly people. It's totally different from Colorado Springs, where I spent most of my childhood. Colorado has a drier and colder climate. There was plenty of spring water, mountains galore, and I didn't find that my allergies were as triggered there.

Louisiana is known for its large oak trees and dangling Spanish moss. The trees and pollen can be huge triggers for me and my eczema. Since developing full body eczema in 2020, I am still trying to mentally and physically recover. I am a professional model and social media influencer, so a large part of my career involves my outer appearance.

When my skin is irritated or flared up, it affects my mental health, which in turn affects my day-to-day life. Taking time to heal and treat my skin is time- and energy-consuming. It's like a part-time job. I've had to retrain my brain, fall in love with the current version of myself and re-define my concept of beauty.

To me, beauty is a feeling. It's something that starts from within and radiates around you. Beauty comes in all colors, shades, textures, ages and sizes.

Photo Credit: Taylor S. Hunter

With eczema, I have realized I am beautiful in all stages. No matter what my skin looks like. When I believe I am beautiful no matter what, it is reflected in my appearance and aura.

I was first diagnosed with eczema as a baby. My mom used to put socks on my hands to prevent me from scratching, even while I was still in a crib. Eventually, I grew out of it (mostly), but it returned in full force during my twenties.

My recovery is ongoing. I continue to monitor my stress levels and food triggers like dairy, sugar and alcohol to ensure I don't have as many flare ups. I am gentle with myself when I get itchy and try to stop the itch immediately instead of surrendering to it and having a full-blown scratch attack. I am mentally triggered every time a small rash appears, in fear that it will consume my entire body again.

Too often, people think it's a simple rash and something that only affects your exterior. In reality, it affects all of you. If you allow it, eczema can consume your entire life.

For me, the hardest part of eczema is being constantly mindful of your triggers. I can't just wear any lotion or beauty products with random fragrances. I can't be around animals without being afraid of breaking out into a rash. It's so unpredictable and sometimes it can feel like a never-ending battle. There was a moment I thought my eczema may never heal and I would never feel beautiful again.

In my experience, the flares directly correlate with stress and anxiety. This doesn't help because as most eczema warriors know, eczema can cause stress and vice versa. So despite the scale of the flare up, I've discovered that it's best to maintain calm and be gentle with yourself in order to heal. Remember that stress weakens your immune system and when your immune system is hampered, it affects the rest of your body.

I've learned that your body is happy when your mind is happy. So if you find yourself getting consumed by stress, you can practice breathing exercises, do yoga, meditate, spend time with your loved ones, have a solo dance party or spend time outdoors to get grounded.

During my flare ups, I sometimes get dressed up and take photos of myself just to feel better or "normal." I remind myself that everyone has flaws and mine happen to be on my skin. I try to remember all the things I find beautiful about myself and focus on those things more than my flare ups. Then my confidence shines from within and I no longer feel so self-conscious about my eczema.



Photo Credit: Cynthea Corfah



Photo Credit: Taylor S. Hunter

Life with eczema has taught me that I can do anything I set my mind to if I am gentle with myself, have patience, advocate for myself and remember that I know myself and my body better than anyone else. I now realize that anything can heal with time, but you have to have faith and trust.

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IT'S ALL RELATIVE

Skin Barrier Basics for People with Eczema

By Angela Ballard, RN

NEA QUIZ

Nearly 40% of people who reported spending more than \$100 a month to treat their atopic dermatitis also report their AD flaring:

- A. 5 or more days in the previous month
- B. 7 or more days in the previous month
- C. 9 or more days in the previous month
- D. 11 or more days in the previous month

See the answer on the bottom of the next page!

Your skin is your first line of defense against the outside world — fending off germs, chemicals, allergens and more. But if you have eczema, your skin barrier may be weakened, leading to a cycle of uncomfortable dryness, irritation and inflammation, symptoms which, on their own, can contribute to even further skin barrier degradation, worsening symptoms and so on.

Fortunately, when you understand more about your skin barrier, you can take steps to strengthen it for relief of your eczema.

The human skin barrier is basically the uppermost layer of skin containing, among other things, skin cells and specialized immune system cells which make up a physical and functional protection system. Like a wall, this system works to recognize and keep out intruding organisms and substances.

With eczema, however, the skin barrier can't function as effectively and may be "leaky." There are a number of reasons for this. One is that many people with eczema actually have differences in the gene that codes for a key protein called filaggrin. In fact, according to the National Institutes of Health (NIH), up to 30% of eczema patients have mutations in the gene for filaggrin. Filaggrin helps structurally, binding keratin filaments together to strengthen and flatten skin cells. If you don't have enough functioning filaggrin, skin cells can lose moisture, shrink and develop gaps between them (effectively leaving "holes" in the wall of your skin). With loss of moisture, skin also becomes dry and itchy, leading you to scratch or rub, which can further weaken the skin barrier. Inadequate filaggrin production can also impact the skin's pH, allowing abnormal bacterial growth that can prompt immune responses like inflammation.

Lipids are another important part of your skin barrier. In people with eczema, skin lipids can have a slightly different composition and contain less ceramide, a substance that's important for locking in moisture. According to a scientific review in the journal *Allergy, Asthma & Immunology Research*, differences in lipids and inadequate ceramide in people with eczema contribute to dryness, irritation and skin dysfunction.

While this might all sound a bit complicated, Dr. Amy Paller, chair of the department of dermatology at Northwestern's Feinberg School of Medicine, offers some simple advice to help your skin barrier:

"If you are experiencing an active eczema flare, treat it." Inflammation and dryness, she explains, can ruin your skin barrier, so you need to address symptoms correctly with the help of your healthcare professional. They will likely include the following three things as part of an eczema management and skin-barrier-fortifying regimen:



Moisturizing. When you keep your skin moist, you improve barrier function. For more severe dryness, experts with the American Academy of Pediatrics recommend moisturizing after short "soaks" in a lukewarm bath. Thick ointments or creams may be preferable to lotions to prevent skin from drying out while protecting it from irritants. Products may contain ceramides or vitamin B3. Don't apply barrier creams to broken skin.



Minimizing exposure to allergens, irritants and your typical triggers. Common eczema triggers include: dry skin, dust, pet dander, pollen, metals like nickel, cigarette smoke, soaps and household cleaners, fragrances, fabrics like wool and polyester, certain chemicals, dry air and stress. People with eczema tend to have an overactive immune system that when triggered outside or inside the body, responds by producing inflammation. This inflammation can lead to red, itchy or painful skin, a situation that can be both a symptom of and contributor to a weakened skin barrier. This is where the cycle of skin barrier dysfunction kicks in. With eczema, your skin barrier is likely weakened, meaning it is more likely to allow allergens, irritants and triggers to impact it and degrade the barrier even further. The more your skin barrier is weakened, the more irritants and even microorganisms are able to invade and cause problems — like stronger reactions or infections. Your best bet? Try to avoid triggers and break the cycle.



Bathing for skin barrier repair and regulation. Regular, gentle bathing helps remove irritants and dead skin cells so the skin barrier can work to repair itself. Non-soap cleansers, which are low in pH and hypoallergenic, are recommended rather than soap, as they cause less disruption to the skin barrier. Soak in lukewarm water for 10 to 15 minutes, which is long enough to rehydrate but not so long as to further weaken the skin barrier significantly. Apply moisturizer soon after bathing. Consider "soaking and smearing" where you soak affected areas then cover them with ointment. Even topical corticosteroids can be applied to wet skin, immediately after baths, to help capture moisture while also improving medication delivery. For additional benefits, incorporate occasional bleach baths. While most people think bleach baths help skin because they're antibacterial and antifungal, the greater benefit may actually be in their anti-inflammatory properties and ability to help balance skin pH. Dr. Paller said her patients see improved skin barrier function with bleach baths, "My patients tell me this is the best thing they've started to do and it's so easy."

To incorporate bleach baths into your routine, the National Eczema Association recommends ¼ - ½ cup of common 5% household bleach added to a bathtub full of lukewarm water. Soak for no more than 10 minutes two to three times a week. Do not submerge your head and, of course, be careful to avoid getting any of the bath water into your eyes. Supervise children carefully. Rinse off with fresh water and apply moisturizer. If a bleach bath feels uncomfortable because your skin is extremely dry or inflamed, "You can ease discomfort by getting into the bath with dressings still on," said Dr. Margaret Lee, an instructor in dermatology at Harvard Medical School and pediatric dermatologist at Boston Children's Hospital. "This will allow the skin to re-equilibrate and help alleviate some of that initial discomfort of getting into the bath, before you start pulling the wraps off. Another way to help tolerate getting into bleach baths is to put a little antibacterial ointment or petroleum jelly in the cracks of the skin." Of course, if in doubt, talk to a healthcare professional about whether bleach baths are right for you.

Even during an eczema flare, remember, your skin barrier is still doing powerful work to keep your whole body safer and healthier. Nurture it when you can and it will nurture you back.

NEA Quiz Answer:

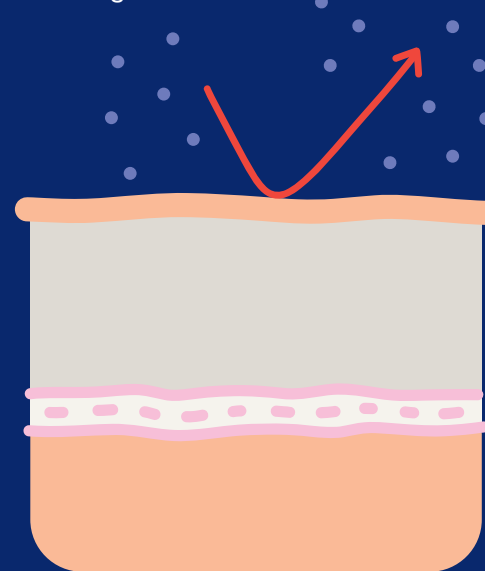
D. 11 or more days flaring in the previous month

Nearly 40% of respondents in a recent NEA-authored study reported more than 11 days actively flaring in the previous month. People spending more than \$100 on their AD every month were also more likely to report minimal disease control (41.1%), the use of three or more prescription medications (39.7%) and the use of step-up therapies (42.3%) such as injectable and oral medications or phototherapy.

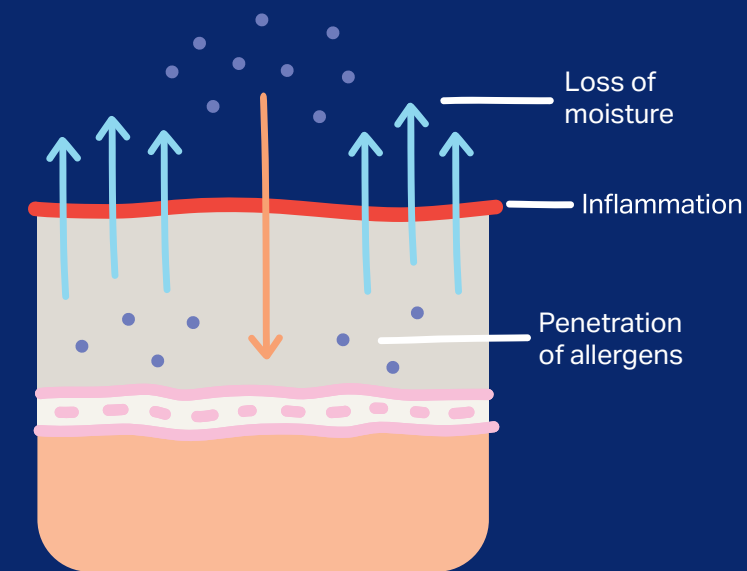
Reference:

Chovatiya, R*; Begolka, WS; Thibau, I; Silverberg, J. Impact and Associations of Atopic Dermatitis Out-of-Pocket Health Care Expenses in the United States. *Dermatitis*: 2021: September 13.

Bacteria & allergens



Healthy Skin Barrier



Damaged Skin Barrier

Illustration by Madelyn Boyle

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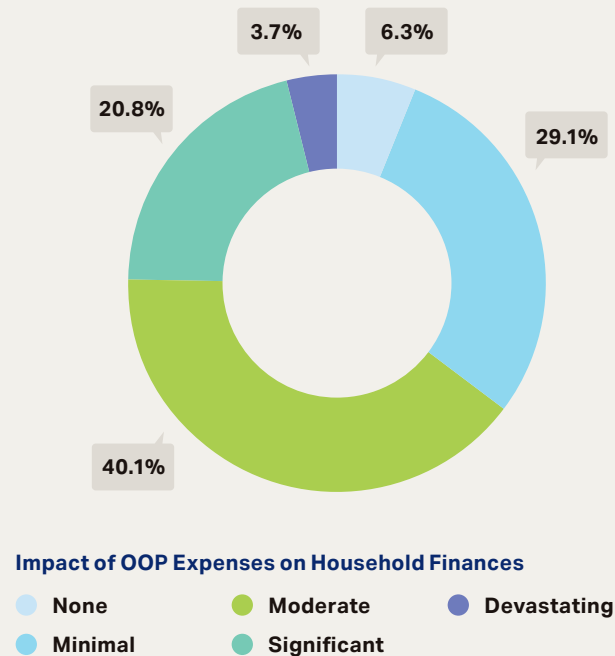


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The Worse it Gets, the More We Spend

New Findings Show Atopic Dermatitis Out-of-Pocket Costs Tied to Severity

Nearly 25% of people with eczema reported significant or devastating financial impact because of expenses related to their condition.

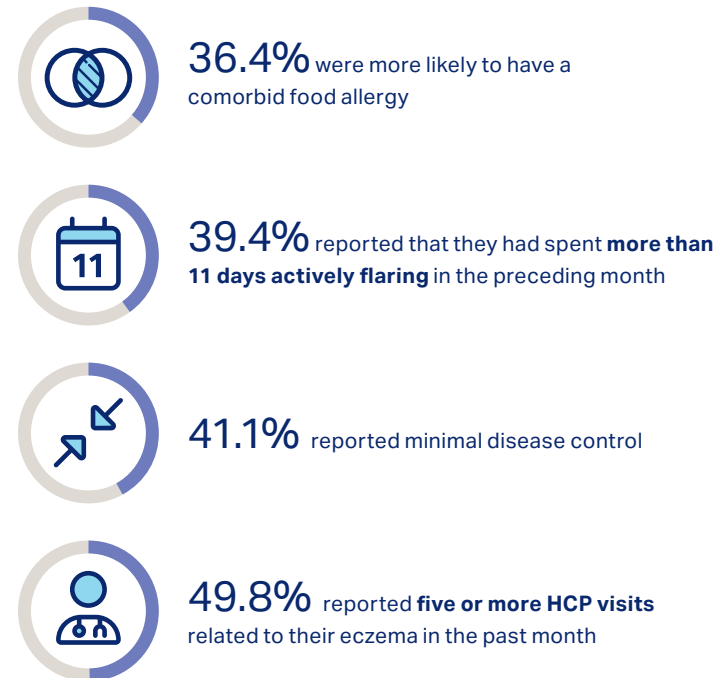


The NEA research team has published its second paper in *Dermatitis* on the out-of-pocket (OOP) costs of atopic dermatitis (AD) in the United States.

Based on a survey of NEA's eczema patient and caregiver community, this body of research is the first to examine the OOP financial burden facing Americans living with AD from the patient perspective. The findings have been analyzed in collaboration with researchers Dr. Raj Chovatiya, PhD (Northwestern University) and Dr. Jonathan Silverberg, PhD, MPH (The George Washington University School of Medicine and Health Sciences).

For more information about this study and other research conducted by NEA, visit: NationalEczema.org/surveys

Of people with eczema spending more than \$100 OOP expenses in the past 30 days related to eczema:



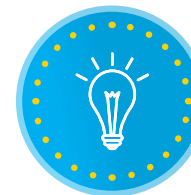
→ OOP survey data demonstrate that severe AD is a positive predictor of harmful financial impact on the individual and/or family with the condition.

Chovatiya, R*; Begolka, WS; Thibau, I; Silverberg, J. Impact and Associations of Atopic Dermatitis Out-of-Pocket Health Care Expenses in the United States. *Dermatitis*: 2021: September 13.

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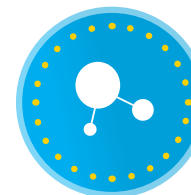


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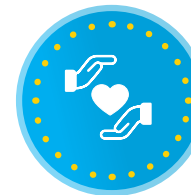
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