



National
Eczema
Association

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NEA Magazine

Research, Support and Education for Those Affected by Eczema

Focus on Eczema

p17

This Eczema Awareness Month, we
want you to focus on eczema – the skin,
the stories, the facts and the research.





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



NEA Magazine

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The Science of Eczema on Darker Skin

Reviewing the research on what's currently known and highlighting the need for improved access to enhanced eczema care for people of color

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

It's October and Eczema Awareness Month is in full swing. This year our campaign is all about focusing on eczema, zooming in to see ourselves and each other, flaring or not. We invited eight members of the community to step in front of the camera to reveal their eczema and share their stories. Take a look on page 17 and join us all month long!

With school back in session, we asked our junior eczema ecz-perts for tips on how they keep their hands busy in class when they're feeling itchy. You might be surprised by some of the great ideas our NEA kids came up with to help their fellow junior eczema warriors! I'm consistently inspired by the resourcefulness and courage of our youngest NEA community members. Read more on page 12.

For our NEA parents, we've included guidance about how eczema can impact our kids' mental health. The daily stress of living with eczema can take its toll on anyone, at any age, and we've provided tips on page 26 from three mental health professionals about when a child might benefit from talking with a therapist.

We're also excited to share that the NEA research team recently published findings from our new study about shared decision making (how patients and caregivers work with their doctors). You'll find excerpts from the study on page 28. We are steadfast in our work to elevate the perspectives of the eczema community in research.

Be sure to check out Dr. JiaDe Yu's advice for how to get the most out of your next dermatology appointment (page 16). And check out page 24 to hear from two allergists and a professional dog trainer on which breeds might work best for families that live with eczema and allergies.

Lastly, 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 preventions, better treatments and - ultimately - a cure. NEA is dramatically increasing its investment in eczema research. We invite you 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

Eczema Expo 2022, Eczema Counts, New NEA Team Members, Eczema Awareness Month

Eczema Counts



NEA joined forces with the Pediatric Dermatology Research Alliance (PeDRA) to create Eczema Counts, a series of games and activities to engage patients, families and researchers together in learning about patient-centered research in childhood eczema. With nine full games coming, you don't want to miss out on this educational (and fun!) research opportunity. Scan the QR code to get in the game and start learning.

NEA Welcomes Six New Team Members

Please join us in welcoming Bryan Mantell to the NEA team as research data analyst. Bryan has a strong analytical background as a scientific programmer, data manager and researcher at the University of Oregon. Bryan has a passion for automation, standardization and open science. At NEA, he will continue to analyze and communicate meaningful data driven discoveries to help with eczema. Welcome Bryan!

The NEA Operations team is also thrilled to welcome five new members to its nearshore development team. Bringing development in-house allows us to move quicker and release new updates more frequently to respond to the dynamic needs of our eczema patient community. Welcome to Walter Garcia, lead developer; Miriam Rodriguez, UI/UX designer; Luis Rodriguez, senior developer; Benedeck Chavez, senior developer; Rafael Velazquez, senior developer.

Eczema Expo 2022 Round Up

That's a wrap on Expo 2022! After three long years we finally convened in person again, this time in Seattle, and it was (almost) as if we hadn't missed a beat. With attendees gathered from all over the country (and even a few international members of the community), the three days brought one extraordinary moment after another. Between sunrise yoga on the terrace overlooking Lake Washington and expert sessions decoding the latest science and research, there was the forging of new friendships and mentorships, the letting loose through karaoke, dancing and spoken word – and the comfort that comes with recognizing yourself in another. Thank you to all who attended in person and virtually. We'll see you next year! Location and details to be announced soon.



Eczema Awareness Month Is Here!

October is Eczema Awareness Month and this year we're asking our community to Focus on Eczema. We conducted a photo shoot with eight members of our community that live with eczema every day. Whether they're flaring or not, when you look at their skin, you'll see skin with eczema: lines, flakes, inflammation, bumps and discoloration. And in case you don't see it, we'll zoom in. We want you to look. We want you to see and understand. We want you to focus on eczema – the skin, the stories, the facts and the research. See more on page 17 and join us on social @NationalEczema using hashtags #FocusOnEczema #EczemaMonth #unhideECZEMA.

NEA Ambassadors' Corner



NEA Ambassadors at Eczema Expo 2022 in Seattle, WA

Summer 2022 was one for the books for NEA Ambassadors! We were able to finally meet in person for the first time at Eczema Expo 2022, and it coincided almost exactly with the program's second anniversary. We came away feeling more connected and invigorated than ever to continue making changes in our local eczema communities.

With more than 200 patient and caregivers across the country, NEA Ambassadors are primed to use our collective voice to raise awareness and reduce stigma during this year's Eczema Awareness Month. You'll find Ambassadors on social media and in their communities sharing information, advocating for better access to care and participating in groundbreaking eczema research.



If you're an adult living with eczema or caregiver of someone with eczema, we invite you to join the NEA Ambassador family and make your voice heard. Learn more and get started today!

GET AHEAD OF ECZEMA AND SHOW MORE SKIN

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

Available for children 6 months of age and older.

- ▶ Fast itch relief*
- ▶ 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; at 2 weeks 18% vs 8% had less itch, respectively. At week 16, 39% of adults saw clear or almost clear skin vs 12% on TCS only. 22% saw clear or almost clear skin at 16 and 52 weeks vs 7%, respectively.

KEVIN,
REAL PATIENT
Individual results may vary.

DUPIXENT
(dupilumab) Injection
200mg • 300mg

HELP
HEAL
YOUR
SKIN
FROM
WITHIN™

— TALK TO YOUR ECZEMA SPECIALIST AND GO TO [DUPIXENT.COM](https://www.dupilumab.com) TO FIND OUT MORE —

INDICATION

DUPIXENT is a prescription medicine used to treat adults and children 6 months 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 months of age.

IMPORTANT SAFETY INFORMATION

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

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

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

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

DUPIXENT can cause serious side effects, including:

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

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

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

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

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

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

Please see Brief Summary on next page.

sanofi REGENERON

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DUP22.03.0113

YOU MAY BE ELIGIBLE FOR AS LITTLE AS A \$0 COPAY.* CALL 1-844-DUPIXENT (1-844-387-4936)

*THIS IS NOT INSURANCE. Not valid for prescriptions paid, in whole or in part, by Medicaid, Medicare, VA, DOD, TRICARE, or other federal or state programs, including any state pharmaceutical assistance programs. Program has an annual maximum of \$13,000. Additional terms and conditions apply.

What is DUPIXENT?

- DUPIXENT is a prescription medicine used:
 - to treat adults and children 6 months 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.
- 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 months 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" 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.
 - **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/dupixent/>.

- 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.
 - The DUPIXENT pre-filled pen is only for use in adults and children 12 years of age and older.
 - The DUPIXENT pre-filled syringe is for use in adults and children 6 months of age and older.
- 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 given 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 too much DUPIXENT (overdose), get medical help or contact a Poison Center expert right away at 1-800-222-1222.
- 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. 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.** Joint aches and pain can happen in people who use DUPIXENT. Some people 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 of DUPIXENT in patients with atopic dermatitis include: injection site reactions, eye and eyelid inflammation, including redness, swelling, and itching, sometimes with blurred vision, cold sores in your mouth or on your lips, and high count of a certain white blood cell (eosinophilia).

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

Manufactured by: Regeneron Pharmaceuticals, Inc., Tarrytown, NY 10591
U.S. License # 1760; Marketed by sanofi-aventis U.S. LLC, (Bridgewater, NJ 08807) and Regeneron Pharmaceuticals, Inc. (Tarrytown, NY 10591)

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RESEARCH

THE SCIENCE OF ECZEMA ON DARKER SKIN

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

People of all skin colors, races and ethnicities can be affected by eczema, yet much of what is currently known has been learned by studying eczema on white skin.¹ Recent studies of the high eczema prevalence in diverse racial and ethnic groups has resulted in calls for more studies on eczema on darker skin or skin of color (SOC).² It is also crucial for diverse patient groups to participate in clinical trials for the rapidly growing treatment options to understand the various drugs' real world applications for all eczema patients. Here we review what is currently known about eczema in SOC and highlight areas of focus for addressing gaps in research and enhancing the care of eczema patients with SOC.

WHAT IS MEANT BY "SKIN OF COLOR"

The true number of skin colors is unknown and may be infinite.³ Historically, however, one way healthcare providers and scientists have referred to different skin tones is through the use of a numeric metric called the Fitzpatrick scale (Figure 1).⁴ Developed in 1975, the scale was originally created to help physicians understand how much ultraviolet light combined with photo chemotherapy (PUVA) should be given to different patients during phototherapy to treat psoriasis.⁵ Dr. Fitzpatrick initially defined

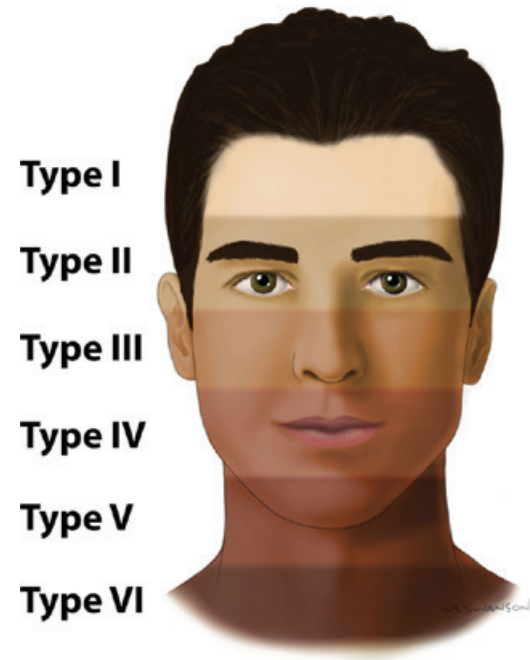


Figure 1: Representation of Fitzpatrick Skin Types I to VI republished with permission from Massie et al., 2019.

a I-IV scale based on patients with white skin reporting redness and tanning reactions to their first summer sun exposure. Type I was “always burn, never tan” and type IV was “rarely burn, tan with ease” with “usually” or “sometimes” burn in between. Types V and VI for brown skin and black skin were added later based on studies of pigmentation after ultraviolet light exposure.^{6,7} Using this scale, SOC is often referred to as Types IV-VI, although individuals with SOC can identify with other Fitzpatrick skin types, highlighting the limitations of this scale.^{8,9} While the Fitzpatrick scale was not designed to be used to discuss race or ethnicity, a recent report suggests this does occur in some clinical settings.^{8,9} The most important take-home is that an “erythema” (redness) reaction to ultraviolet light does not equate to the degree of pigmentation in the skin. A more contemporary and racially and ethnically inclusive definition of SOC was created by the Skin of Color Society to include individuals of Asian, Hispanic/Latino, African, Native American, Pacific Islander ancestry and people of mixed descent.

New methods to objectively quantify skin color using technology called “colorimetry” and “spectrophotometry” which measure the degree of pigmentation (white skin to brown skin) and hemoglobin (red) are being investigated to help give researchers and clinicians a unifying language with which to discuss SOC.¹⁰

PREVALENCE OF ECZEMA IN SKIN OF COLOR

While eczema is a common skin disease, determining the prevalence of eczema in SOC in racial and ethnic populations is difficult, as published studies have not uniformly defined race and ethnicity

categories. Terms used to define groups with regard to race/ethnicity have included White, Black, Hispanic, Hispanic origin, non-Hispanic, African American, Asian or Pacific Islander, American Indian, Puerto Rican, Mexican, Mexican American, Cuban or Cuban American, Dominican, Central or South American, multiracial, multiple races, stratifications by country of origin without reference to skin color and others.¹¹⁻¹⁶ Despite this inconsistency across studies and gaps in data for certain SOC populations,¹⁷ the current understanding of eczema prevalence in SOC has pointed to several key observations:

- ➔ At least 1 in 10 individuals are affected by eczema over a lifetime representing all races and ethnicities.^{14,16,18-20}
- ➔ Although study percentages vary, adults that are multiracial or white tend to have the highest prevalence of eczema.^{12,16,21,22}
- ➔ In the U.S., eczema affects more Black children (about 20%) than white children (about 16%) or Hispanic children (about 8%).²³
- ➔ Black children report more visits to healthcare providers and more prescriptions compared to white children,²⁴ and Black race is associated with higher eczema-related out of pocket costs for eczema.²⁵
- ➔ Black children and Hispanic children tend to have more severe eczema than white children.^{22,26}

Understanding differences in eczema diagnoses, symptoms, severity and treatment based on lighter skin versus darker skin or race or ethnicity definitions is challenging. Dr. Zelma Chiesa Fuxench, MD, of the University of Pennsylvania said, “My impression is that we have a long way to go to fully understand the burden of atopic dermatitis (AD) across patients in the SOC spectrum. We need more studies that focus on the epidemiology of this disease among SOC patients to truly understand how it compares to better studied populations. Not only should these studies be examining the prevalence of AD but also the distribution of disease severity, and presence of comorbid atopic and non-atopic diseases. Another topic of interest would be the disparities in access to care, use of emergency and urgent care services, lack of access to dermatologist and treatment access among SOC patients with AD.” Dr. Andrew Alexis, MD, MPH, chair of dermatology and director of the Skin of Color Center at Mount Sinai agreed, stating that “The majority of the world’s population can be characterized as having SOC, and by the year 2044 more than half of the United States population will belong to a non-white racial and/or ethnic group. Clearly, more studies are needed to understand eczema in SOC.”

CONTRIBUTING FACTORS TO ECZEMA: WHAT IS KNOWN IN SOC

SKIN BARRIER

Eczema is caused by a combination of factors including a defective skin barrier, genetics, each person’s immune makeup and response and environmental exposures (Figure 2). The impaired skin barrier in eczema results in higher levels of water loss from the skin (trans-epidermal water loss or TEWL). Some studies have found that TEWL is greater in Black skin compared with white skin. Further, a study including Asian, African and Danish individuals (total n=71) found

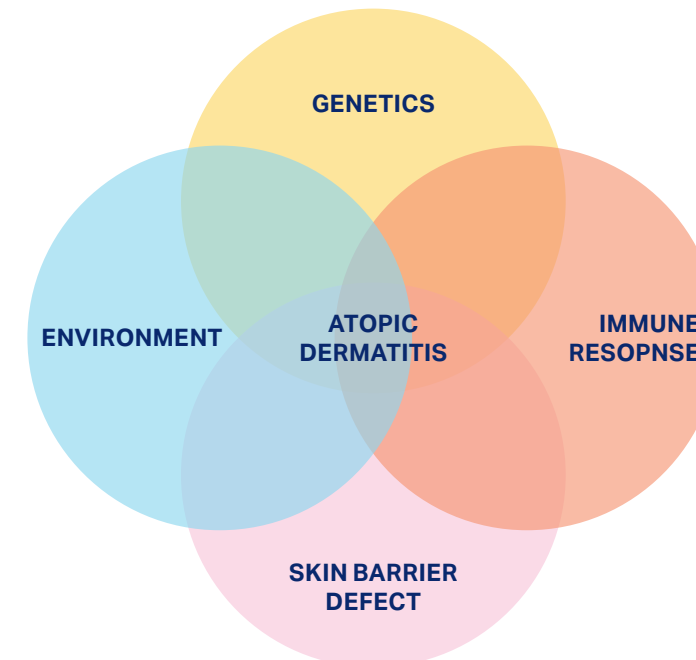


Figure 2: Factors contributing to eczema that may widely differ between individuals.

significant differences in the fat (lipid) content of the outer layer of the skin that protects against water loss (the stratum corneum), with Asians having the highest lipid content, Danish having intermediate values, and Africans having the lowest values.²⁷ While studies are limited they suggest there may be racial variations in the skin barrier that contribute to eczema.

GENETIC FACTORS

The most common genetic mutation associated with susceptibility to eczema is *filaggrin* (*FLG*) whose protein product is responsible for binding specialized skin cells called keratinocytes together to create the structure of the stratum corneum. More than 300 different kinds of mutations within the *FLG* gene have been found and more than 20 of them have been associated with susceptibility to eczema.²⁸ Four *FLG* mutations are consistently associated with eczema in patients of European ancestry and these have been the most commonly studied mutations. Studies of patients with East Asian ancestry show that there are more kinds of *FLG* mutations but only one has been associated with eczema in Chinese, Japanese, Korean and Taiwanese populations.²⁸ Dr. Chiesa Fuxench says, “With respect to improving our understanding of the pathophysiology of AD, studies are needed that examine the genetics of AD across diverse populations. The *FLG* gene is the strongest known genetic risk factor for AD. However, most studies have primarily focused on those of European or Asian descent with few studies focused on those of African or Latinx ancestry.” Surprisingly, several studies did not detect *FLG* mutations in people with African ancestry until Dr. David Margolis, MD, PhD, of the University of Pennsylvania and colleagues studied 262 American children of African descent and found that 12.2% had *FLG* mutations of any type, nine different *FLG* variants were detected and those nine

variants associated with more persistent eczema than children with the normal *FLG* gene.²⁸ A subsequent study showed that *FLG* variants in African Americans correlated with African *FLG* variants and *FLG* variants in European Americans correlated with European *FLG* variants despite the mixture of the two populations in America.²⁹ Overall, the number of *FLG* variants differs between African Americans and European Americans,²⁹ yet a recent study found these differences do not appear to explain AD risk between these racial groups.³⁰

IMMUNE SYSTEM FACTORS

The last several years have seen an expansion of studies investigating the complex immune pathways underlying AD, and more specifically what immune pathways are regulating AD in different populations. An initial study looked at the types of T helper (Th) cells, a type of immune cell, in the skin of Asian (Japanese and Korean) AD populations compared to European American AD patients.³¹ Japanese and Korean AD patients had higher numbers of certain types of T helper cells (Th17 and Th22) that cause inflammation than European American AD patients.³¹ A further study then looked at the T-cell-produced messengers (cytokines and interleukins) in the blood of Japanese and Korean vs. European American patients, finding important differences in these messengers between groups.³² A third study comparing Han Chinese with European American AD patients again found higher numbers of Th17 inflammation-causing cells in Chinese patients.³³ Comparing African American with European American AD patients, researchers found lower numbers of certain Th1/Th17 inflammation-causing cells and higher numbers of other inflammation-causing cells (Th2/Th22) in the affected skin from African American patients.³³ As new therapies for AD targeting different immune pathways are developed, understanding immune system similarities and differences between racial or ethnic groups will help guide a more targeted treatment selection approach for diverse eczema patients.

TREATMENT OF ECZEMA IN SOC

The first step toward treatment of eczema in SOC patients is appropriate diagnosis, yet this can be challenging. Dr. Alexis said, “There are major differences in the appearance of eczema in SOC. The severity of eczema in SOC can be easily underappreciated since we do not really see the bright red color associated with eczema in white skin, the colors can range from grey to reddish brown to purple

“The severity of eczema in SOC can be easily underappreciated since we do not really see the bright red color associated with eczema in white skin, the colors can range from grey to reddish brown to purple or purplish grey.” ~ Dr. Alexis

or purplish grey. Beyond color, another example is called the follicular pattern – tiny bumps which are extremely itchy and might correspond with hair follicles. Eczema in SOC may also appear to be other types of skin diseases, leading to misdiagnosis.”

Based on the physical characteristics of SOC that may impact the skin barrier as discussed above, SOC is often more dry than white skin.³⁴

Based on the physical characteristics of SOC that may impact the skin barrier as discussed above, SOC is often more dry than white skin.³⁴ Efforts are being made to analyze what types of moisturizers work best to treat dry skin in different populations including those with SOC, to enhance this cornerstone of AD treatment.³⁴

Individuals with SOC can effectively use all available therapies for AD; however in some cases additional considerations may be needed. For example, as SOC contains more skin pigment that acts as a UV filter, higher phototherapy doses may be needed and there may be longer times before treatment efficacy. An objective system has not yet been established to predict UV light responses in SOC since the Fitzpatrick scale was not developed for SOC, so determining optimal dosing for these patients can be difficult.³ Patients with SOC can experience post-inflammatory pigmentation changes, both hyperpigmentation (skin darkening) and hypopigmentation (skin lightening).^{35,36} More studies are needed to address how pigmentation is impacted with treatment of AD in SOC.

Finally, the appearance of AD lesions and erythema (redness) in SOC can impact the assessment of treatment outcomes. Often “redness” is evaluated as part of the scoring system for clinical trials and to evaluate how well a drug is working for someone’s eczema, but “redness” can appear as pink, brown or purple depending on different skin color tones. A study from 2015 tested four visual AD outcome measures assessments Eczema Area and Severity Index (EASI), objective-SCORing Atopic Dermatitis (oSCORAD), Three Items Severity index (TIS) and Six Areas, Six Sites Atopic Dermatitis (SASSAD) in 18 patients with various levels of skin darkness (African, Asian, Caucasian and Indian descent). The outcome measures were not as reliable and had reduced validity in highly pigmented patients because of the varying ability of healthcare providers to judge redness in certain skin colors.³⁷ A subsequent study including 11 light-skinned patients and 14 patients with SOC evaluated EASI, oSCORAD, Investigator’s Global Assessment (IGA) and a novel greyscale that assessed clinical-sign greyness, graded from 0 to 3 (no grey = 0 to dark grey = 3) based on the average greyness of the affected area rather than redness. In this study EASI was found to be reliable in all skin colors and was proposed as the best outcome measure for AD clinical trials globally.³⁸ In one study, after adjusting for the “redness score” in the oSCORAD scale, Black children were found to have six times greater risk of severe AD compared to white children, indicating that use of this redness score can lead to underestimating the severity and treatment outcomes of AD in Black

children.^{39,40} Improved training on how skin diseases appear in SOC and greater inclusion of people with SOC in the validation of outcome measures for clinical trials will help improve the utility of these assessments in the future, influencing both diagnosis of eczema symptoms and treatment of eczema in SOC.

EFFORTS TO ADDRESS SOC UNDERREPRESENTATION AND DISPARITIES IN ECZEMA KNOWLEDGE AND TREATMENT

An important acknowledgement across medicine is that there has been a significant gap in representation of SOC in medical literature, educational materials, clinical trials and healthcare providers.^{4,41-43} Researchers recently analyzed the diversity in medical photographs from six plastic surgery journals and the New England Journal of Medicine over the past 30 years. Among the 24,209 color photographs depicting skin, 78% were of white skin and only 22% were of non-white skin.⁴ Of four main textbooks traditionally used to train U.S. dermatologists to diagnose skin diseases, the majority of images were of white skin, and in all cases the percentage of images depicting darker skin were not representative of U.S. populations.⁴³ A systematic review of 58 U.S. dermatological clinical trials that recorded race/ethnicity found that around 75% of participants were white.⁴⁴ Lastly, the representation of SOC among dermatological healthcare providers is behind the increasing U.S. population trends with 3% Black and 4.2% Hispanic dermatologists in the workforce compared to 12.8% Black and 16.3% Hispanic individuals in the general U.S. population.⁴²

Importantly, there are individuals and organizations now working to increase knowledge about SOC and improve representation of images in the medical literature, including skin diseases like eczema.⁴⁵ New guidance for proper lighting for medical images of SOC was recently published in the British Journal of Dermatology with the goal of increasing the number of quality SOC images in educational and medical literature.⁴⁶ Dr. Nada Elbuluk, MD, at the Keck Hospital of the University of Southern California said, “New textbooks and educational resources are being developed and the American Association of Dermatology is working on a SOC curriculum. Journals are diversifying their editorial boards and the major meetings of the scientific dermatology societies are consciously selecting more diverse content of what is presented.”

There is also great need for dermatologists with expertise in SOC. To address health disparities and issues of access to healthcare, SOC clinics are opening around the country. The first of these was the SOC Center at Mount Sinai West in New York City founded by Dr. Susan Taylor, MD, growing to 15 different centers by 2020.⁴⁷ The goals of these centers are to: 1) further the care and research of conditions common among persons of color; 2) prepare residents to treat skin of color; and 3) educate the medical community and public.⁴⁷ The Skin of Color Society, established in 2004, additionally drives this movement by promoting research and education of fellows, associate members, residents and research fellows through grants, mentorship and industry partnerships. Dr. Elbuluk also directs the Skin of Color and Pigmentary Disorders Program to promote research and education and said, “The field of dermatology is underutilized as a specialty

by people of color. They feel that they are being misdiagnosed and undertreated. Skin diseases in skin of color have to be approached differently. At these SOC clinics, patients of color can come and feel like people there have expertise and cultural understanding. I wanted a place that would change the narrative, where patients really felt heard and could see that their conditions were getting better.”

With these dedicated clinics, and broader efforts to address knowledge and research gaps related to SOC, the diagnosis, care and treatment of eczema in SOC is poised to dramatically improve. Efforts to address and reduce the gaps should parallel the evolving racial/ethnic makeup of the AD community and the U.S. population.

TAKE HOME POINTS:

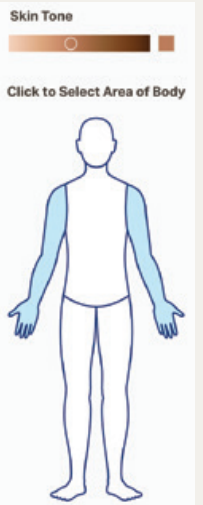
- Much of what is currently known about eczema has been learned by studying white skin. Healthcare providers and researchers are acknowledging and addressing these gaps to improve knowledge and care of eczema in SOC.
- Skin, genetic and immunologic factors that contribute to eczema can differ between racial and ethnic groups and impact prevalence, persistence and severity of eczema in SOC.
- Increasing representation of SOC in medical education, medical literature and the healthcare workforce, including specialized clinical centers, will improve healthcare for people with SOC.

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Introducing the Atopic Dermatitis Visual Guide

People of all skin colors, races and ethnicities can be affected by AD and it can look very different from one person to the next based on skin tone (as well as level of severity, affected part of the body, etc.). We created the Atopic Dermatitis Visual Guide to help patients, caregivers and healthcare providers see a full spectrum of eczema and filter images by skin tone and body part. Check it out at NationalEczema.org/ADVisualGuide.

The Atopic Dermatitis Visual Guide was funded in part by an educational grant from Sanofi and Regeneron, as well as the American College of Asthma, Allergy and Immunology.



5 Tips From Kids For Kids: How to Keep Your Hands Busy in Class (Instead of Scratching)

By Steve Nelson



The clock is ticking down to those final minutes before recess, or maybe you just sat down for a really hard spelling test and . . . your skin is begging to be scratched. Fear not, itchy friends: we're here to help. Our junior eczema ecz-perts have shared a few tips on keeping your hands busy in class, instead of scratching.

#1: Draw or write about something totally unrelated to your eczema

The majority of our eczema ecz-perts said they liked to draw, doodle or scribble in the margins of their notebooks whenever they felt the urge to scratch. Be sure to get permission first, so your teachers know this actually helps you pay attention.

Bryson Doyle lives with severe eczema and recently started his junior year of high school. "When I feel itchy in school, I will usually start drawing, writing and tapping my pencil," he said. "Anything to take my mind off the itch."

Distraction is key. The urge to itch originates in your brain, so let your mind relax. "With multiple teachers and classrooms," Bryson explained. "I had to learn when and where my skin would start flaring so that I knew what to bring with me. It's also so important to communicate with your teacher about what you need."

#2: Ice is nice: cool down those flaring hands

Eczema affects everyone differently. But if cooling your hands down (instead of scratching) sounds like it might help, it's worth giving it a shot. Kiley Anderson is an 8-year-old with eczema who usually keeps a pencil and eraser in her hands to avoid scratching. But when that doesn't work, Kiley's dad, Jaylin, said that if "Kiley's super itchy, her teacher will allow her to go to the office and put an ice pack on her hands." Kiley said that taking a short break in the nurse's office, where her school keeps an ice pack, helps her avoid "feeling uncomfortable around her peers." Since stress can increase the likelihood of a flare, comfort is key to minimizing itch.

Chelsea Maclane's daughter, Naomi, lives with eczema and recently started fourth grade. Naomi tends to scratch her fingers under the table and her teachers don't always notice, Chelsea said. "We have used ice packs for Naomi with some success," she said. "She has one in her lunch box she can pull out if she needs to."

Most schools will have a disposable ice compress in their first-aid kit. And, like Naomi, there are plenty of reusable options that kids can retrieve from their own lunch boxes or backpacks if their teachers allow them in class.

#3: After moisturizing, massage your own hands for a few minutes

Massaging your own hands will decrease stress, calm your mind and help control your urge to scratch. And this tip isn't just for older kids. Ella Chnelich just started second grade and has lived with severe eczema all her life.

"I used to massage Ella's palms when she was little," said Amy Chnelich, NEA Board Member, about her daughter Ella. "Rubbing Ella's hands with lotion would soothe and distract her from itching. Now, Ella will massage her own palms to help distract her if she's feeling itchy." When Ella started kindergarten, Amy was worried about how Ella's itching would distract her in class. But two years later, Ella has become an expert at massaging her own hands instead of scratching.

"I wish everyone knew that kids with eczema are ALWAYS listening and learning," Ella said. "Because kids want to do the things that make us better all on our own."



Amy and Ella, photo courtesy of Amy Chnelich

#4: Squeeze the living daylight out of your stress ball

Applying pressure, instead of scratching, isn't just for elementary-aged kids, either. NEA Ambassador Jeremy Paredes, a sophomore at Georgia Tech University, knows how to keep his hands busy, too.

"With school comes stress and the unknown," Jeremy said. "With severe eczema, we tend to overthink how our skin looks to other people all the time. When in reality, the majority of our battle is an internal struggle. For me, squeezing a stress ball helps me limit my eczema flare ups and helps me destress."

#5: Sit in the front row of your class

We'll admit: this tip isn't for everyone. But if you need the extra motivation to keep your hands from scratching, it might help to put yourself in a place where your teacher can see you and help you stay focused. Chelsea mentioned that sitting in the front of the class helps her daughter Naomi focus during longer lectures or whenever her mind wanders.

In college, too, Jeremy takes advantage of how often the first row stays empty in many of his lecture classes. When you know the teacher can see you, you know they can see you scratching, and sometimes that's enough motivation to stop.



Bonus tip for caregivers: talk to your child's school administrator before school

Every teacher will likely have their own rules about what kids can keep on their desk and within reach during class. This is where the younger kids need your help the most, and this is especially helpful for students who'd rather avoid any extra attention in class. By involving the school's administration early on, you stand a better chance of getting your teacher aligned with your child's individual needs. There might be some situations where you're asking the teacher to bend the rules a bit, and this is where having the administration involved can help.

"We communicate openly about Ella's needs with our teachers and school administration," said Amy, about her daughter. "Ella prefers to keep a low profile with her eczema. If her teachers notice that she's itching, they let her take a walk to the bathroom or to the school nurse. Sometimes just stepping out of the classroom helps her stop the itch cycle."



GET THE FACTS

Hard Water and Eczema

By Suzanne Boothby

Mineral deposits are a natural part of tap water – but what happens when the water from your faucet is full of extra minerals like calcium and magnesium? Research suggests that mineral-rich water, also known as “hard water,” can negatively impact eczema symptoms and introduce atopic skin conditions early in life.¹

A 2020 review of 16 previous studies concluded that exposure to hard water could worsen symptoms of atopic dermatitis (AD) and increase of the risk of eczema in young children. “Patients with eczema are much more sensitive to the effects of hard water than people with healthy skin,” said Dr. Simon Danby from the University of Sheffield’s department of infection, immunity and cardiovascular disease in a statement.²

Let’s explore the facts about hard water and review what you can do about it.

What is hard water and do you have it in your home?


The U.S. Geological Survey (USGS) defines water hardness as the amount of dissolved calcium, magnesium and other minerals found in water.³ Water hardness can vary throughout the country, but areas in the West and Southwest, such as Las Vegas and Phoenix, are known for having it.^{4,5}


If you’ve ever felt a slimy or chalky residue after washing your hands, that might be a sign that you have hard water. Spots on your glasses after a round in the dishwasher can also be a clue. Hard water can also damage fabrics and clothing.


How does this residue get there? In general, our drinking water comes from two main sources: 1) surface water such as creeks, rivers and lakes; and 2) groundwater, found below the earth’s surface in cracks and spaces near soil, rock or sand. Water from both source types must be treated before we drink or bathe in it, but the hard water comes from groundwater where the water interacts with rocks such as sandstone, granite and limestone picking up additional minerals.


There are also home water hardness tests available for purchase. Water hardness is commonly measured in milligrams per liter (mg/L) or parts per million (ppm).

The U.S. Geological Survey offers general guidelines to help determine your water quality:

 **Soft water:** 0-60 mg/L or ppm

 **Moderately hard water:** 61-120 mg/L or ppm

 **Hard water:** 121-180 mg/L or ppm

 **Very hard water:** Over 180 mg/L or ppm.

If your home or work has hard water, could it be affecting your skin?

If you’re still reading and curious, you might have hard water in your home and you want to know what to do about it. Minerals found in hard water are not problematic to drink and are not known to cause any adverse health issues.⁶ However, they can accumulate on surfaces, leading to clogged pipes or damaged water heaters. Over time, topical exposure to hard water can also dry out your hair and harm your skin barrier. In fact, living in an area with hard water is associated with an increased risk of eczema, according to a study from researchers in London.⁹

“By damaging the skin barrier, washing with hard water may contribute to the development of eczema – a chronic skin condition characterized by an intensely itchy red rash,” said Danby, lead author of the study.

If hard water is affecting your eczema, this is how a water softener might help

If you are concerned about hard water, you may consider getting a water softener, which is similar to a water filter, as it works to remove any unwanted mineral compounds. Water treatment can improve hardness issues, according to the Water Quality Association, a nonprofit international trade association representing the water treatment industry.¹¹

Pooled evidence from meta-analysis shows hard water likely negatively affects AD, but interventional studies thus far have not shown benefit overall. The effects of hard water seem most serious in conjunction with filaggrin mutation and disruptions in the skin barrier.¹²

A trial called the Softened Water for Eczema Prevention (SOFTER) is underway to investigate whether water softeners can help reduce the risk of eczema in babies.¹³ This study offers the first major look at the impact of using water softeners on babies in their own homes.

Other helpful water tips

Unsure about what’s in your water? The EPA requires community water systems to deliver an annual drinking water quality report (also known as a Consumer Confidence Report) to their customers each year in July. Educational info including the amount of minerals in your water should be in that report, along with contact information for your water provider. **If you are having trouble finding information, you can call the EPA’s Safe Drinking Water hotline number: 1-800-426-4791.** If you are one of the more than one million households that get their water from a private well, then you do not receive a water quality report, but you can visit the CDC’s Private Ground Water Wells page to get more info about testing your well.¹⁵

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5 Ways to Better Prepare for Your Next Dermatology Appointment

By Steve Nelson

How can you make the most of your next dermatology appointment when you might only have 15 minutes to ask all your questions? The answer is to come prepared. Nobody likes having homework, but setting aside time to prep for your next appointment will help you make the most out of every minute you get – and in the long run your skin will thank you.

To help save you time, we spoke with Dr. JiaDe “Jeff” Yu, board-certified dermatologist at Massachusetts General Hospital, and asked him what he wished more patients did before coming in to see him. He gave us the following five key takeaways.

#1. Bring a list of all your current and previous medications

Make a list of everything you’re taking, Dr. Yu said. Include the dosage, frequency, brand (or generic) and indicate how long you’ve been taking the different medications. Be sure to make note of what helped and what didn’t. “For example, if you’re going in to see someone for your eczema,” Dr. Yu said, “make sure you have a list of which topical steroids or other steroid medications you’ve tried.” This will allow you and your provider to make a shared decision and better informed recommendation for your treatment plan.

#2. Bring a complete timeline and description of your current symptoms

Write a chronological summary of your current reason for seeing the doctor. “A clear history of your rash, for instance, can be very helpful for your doctor,” Dr. Yu said. “A timeline of when the rash started, who you saw for it and what you did to treat it can help concisely delineate your medical history.”



#3. Bring the results of any previous biopsy or lab work

Telling your provider about your past lab work or any biopsy results can be very helpful, Dr. Yu said, “since it prevents us from having to ‘recreate the wheel’ if you’re a new patient.” This may also save you time and money by avoiding a lab test you’ve already had done.

#4. For follow-up visits, focus on what worked or didn’t work

Consider writing down what happened between your healthcare appointments. If you’ve seen a dermatologist before, Dr. Yu said, and you’re going in for a follow-up visit, make sure you’re able to verbalize what has transpired since your last visit and whether the interventions provided were helpful. Even a short list of bullet points may help you to quickly and effectively provide your doctor with a summary of your recent care.

#5. Organize your eczema photos into a single folder

According to Dr. Yu, pictures of your eczema can be helpful. However, Dr. Yu advises his patients to organize photos of your skin condition in a folder. “Patients will sometimes spend minutes scrolling through photo albums looking for that photo of the rash a few months ago,” he said. “This takes critical time away from your appointment which is better spent coming up with a plan with your dermatologist.” If it’s easier for you to track all the information in one place, consider downloading EczemaWise and start tracking your symptoms and triggers today.



Focus on Eczema

For Eczema Awareness Month, we conducted a photo shoot with eight members of our community that live with eczema every day. Whether they’re flaring or not, when you look at their skin, you’ll see skin with eczema: lines, flakes, inflammation, bumps and discoloration. And in case you don’t see it, we’ll zoom in. We want you to look. We want you to see and understand. We want you to focus on eczema – the skin, the stories, the facts and the research.

Raelle

Philadelphia, PA

Me: Existing within nature fills me more than anything and I never grow tired of following blue skies, evergreen trees, mountains and streams.

Me & my eczema: I appreciate life much more than the average person who doesn't have extreme chronic illness. With the pain came resilience that kept me strong through many battles in my life. It gave me the wisdom to focus on things that are beyond the physical and to lean on others so that I didn't have to take on all of the weight. There is power and strength in seeking help, community, and ease of life.



Lisa

Marin County, CA

Me: I fill my days working part-time, volunteering for various non-profit organizations, hiking and traveling as much as possible.

Me & my eczema: I remember being Saran-wrapped at bedtime around my elbows and knees at a young age and I remember begging my mom to skip the middle school gym classes for swimming. My embarrassing red rashes were easy to cover up but not in a swimsuit. I had buried that memory so deep I almost forgot it ever happened. Once I realized this is a common story among eczema patients, I found I was not alone. I found my voice.



Aisha

Olympia, WA

Me: I am on my journey to become a spiritual healer and hope to enter the medical field with a holistic approach to westernized medicine.

Me & my eczema: It was challenging to show my skin in shorts or tank tops because the topical steroids left permanent scarring and darkening. I did not want my peers to ask about the dark patches or deal with school bullies because I had enough of the lack of self-esteem and feeling inadequate about myself. Thanks to the support of the eczema community, I am no longer afraid of my skin, nor do I have to hide from it, I feel invincible. I no longer wish to hide my disease from myself or anybody. I have learned to embrace my superpower.



Jim

Sacramento, CA

Me: I'm a cat dad who loves reading, walking barefoot, creating podcasts and performing in community theater.

Me & my eczema: When my eczema became severe, I was prescribed multiple courses of prednisone, UV light radiation, topical steroids and methotrexate, but nothing worked. I had to look outside of my health coverage and I found a clinical study on a new injectable biologic treatment. I was accepted into the study, and it successfully treated my eczema. Today I help empower and inspire others that may be going through a similar experience.

Alexis

Forest Hill, MD

Me: I've always been an artsy person and I'm ready to bedazzle anything in sight. One of my favorite activities is making tiny furniture for the squirrels that come to my porch.

Me & my eczema: My personal eczema journey has had almost equal parts ups and downs. I struggled with self-esteem for a very long time during my teen years. I tried to hide my condition because I was embarrassed; it wasn't "normal" so naturally I thought it was ugly. My confidence took a turn for the better after sharing on Instagram unfiltered photos of life with eczema. I received wonderful feedback and what started as a condition I was ashamed of became the thing I am most thankful for.



Andrea

Bridgeport, CT

Me: I am proud to call myself a mom to all my kids, including human babies and five fur babies.

Me & my eczema: The journey with my eczema wasn't easy to deal with, especially as a pre-teen in middle school. I was bullied and made fun of for the way my eczema looked around my mouth. Kids said mean, untrue things about me. As I grew older I was able to develop a thicker skin, figuratively speaking. Since then my eczema journey has become more enjoyable. Finally I was able to be my true self living with eczema and advocate for others.



Morelia

Mission Hills, CA

Me: I'm a college freshman who enjoys hula dancing. I've been studying traditional Hawaiian hula for about 8-9 years. I was also on my high school's wrestling team and competed in the Los Angeles Marathon twice.

Me & my eczema: I've had moderate to severe atopic dermatitis since the beginning of my childhood. In fourth grade, I was eating lunch when I pulled up my right long-sleeve to reveal my elbow eczema. One of my classmates said something along the lines of my skin being disgusting or gross which made me feel terrible about myself. Since then, I've grown, and I now normalize my eczema. When people ask or have concerns about my skin, I use it as an opportunity to educate them.



Stephen

Ontario, Canada

Me: I'm just another gamer, Swiftie, and I like to play with spreadsheets to draw conclusions like which french fry size gets me the most per dollar.

Me & my eczema: It started when I was 4 or 5 and got to its worst point in the years after graduating university. Eventually I discovered treatment options that reduced my eczema to a mild inconvenience. At one point the stress of moving to a new city caused me to have flares unlike any I'd ever known, keeping me up all night scratching and affecting my work and relationships. I was willing to try anything to get sleep. Browsing through the discount store, I thought children's handcuffs could be the answer to keep myself from scratching, but they barely fit, and only made it worse. Adult handcuffs could be a more viable solution.



Sharing My Son's Eczema Story Is Like Opening My Heart

By Maisie Wong-Paredes



All photos courtesy of Maisie Wong-Paredes

My name is Maisie, and I live in Alpharetta, Georgia, about 45 minutes from where my sons Jeremy and Joshua attend Georgia Tech University.

Facing the challenges of eczema in young children

Within months of Jeremy's birth, we knew he had eczema. Our older son, Joshua, was 2 years old at the time, and he was barely healing from his own eczema when Jeremy was born, and the process started all over again: eczema, food allergies and asthma. As babies, both boys had eczema breakouts all over their faces, which kept them from sleeping at night because they were itching and scratching so much.

The boys were born in the San Francisco Bay Area and I remember how bad Jeremy's asthma got during the wildfire seasons; they landed him in the ER multiple times. When Jeremy was barely 5 years old, we moved to Shanghai, China for three years, and when we moved back to the United States, when Jeremy was about 8, his eczema got really bad again.

We saw dermatologist after dermatologist and had tried everything. "Done this, done that, tried everything." I wanted to say to them: "Tell me something that I don't already know!"

Every family faces different challenges with eczema

Eczema took away a lot of sleep during those early years. Other parents said we should try sleep training, but I realized after three or four nights of failed sleep training that Jeremy wasn't sleeping because he was miserable, itching and scratching. As Jeremy got older, I was told I was "coddling" him too much, that I did too much for him. What they didn't realize was that "normal" activities like taking a shower isn't a quick five minutes, it's an ordeal, taking 45 minutes because he has to apply medicated creams, then lotion, and stand there while they dry before getting dressed. So a lot of parenting advice (solicited or not) we just had to throw out the door. And it's important for parents to be okay with that. With eczema in particular, the norms didn't apply.

Yes, there were things I wish I had done differently. But much later in life, I realize we parents do the best we can with what we know at the time. We can't feel bad about it. We have to let that go. Parents carry too much guilt as it is. We don't need to pile more on. It's hard not to, but we can't keep questioning our decisions and stay sane!

When Jeremy got to high school, I tried to take a step back, so he could learn to become more independent. I did, though, push him to build relationships with his high school counselor, his soccer coach and his basketball coach, who had coached him since fifth grade, so that he had support at school when he needed it. I was fortunate that his friends and the parents of his friends were watching out for



Maisie and Jeremy at Eczema Expo 2022

him, too. They felt safe texting me to let me know when Jeremy was having a really bad day so we could intervene and cheer him up.

Getting educational support from the school administration

Jeremy didn't like to talk about his eczema much. When it got really bad, and Jeremy was missing school, I emailed his teachers and let them know. If the kids can't do it themselves, the parents can help build a trusted support network. Eczema is not considered a disability, but we were able to set up a 504 plan for him — an official school plan to give him extra support—because he was missing so much school already.

Traditionally, when I've heard other parents talk about it, the 504 plan is usually for kids that need extra time taking tests, or whatever their individual need is. When things were at their worst for Jeremy, one of his teachers said, "let's look into doing a 504 plan for Jeremy." The 504 plan gave Jeremy the ability to leave class when he needed to, for example, to go to the clinic and wet wrap (multiple times a day). We're so fortunate we had an open line of communication with his teachers, coaches, nurses and school support staff: everyone helped.

Through all the struggle and pain, I've tried to shield Jeremy from my emotions because I didn't want him to know I was upset. I've cried in the closet many times. But I also learned that Jeremy didn't want to worry me and felt very bad thinking he was the cause of my being upset.



Mental health is a very real challenge for our kids. And with eczema, it's even more compounded. The eczema is visible but the emotional wounds are often hidden. There isn't much awareness of the emotional toll eczema has.

It's been a very long roller coaster journey with eczema. Jeremy is now a rising sophomore in college. With the help of new meds and a consistent self-care routine, Jeremy is managing his eczema well (he finally owned his self-care after seeing results when he takes care of himself). The journey with Jeremy and eczema, while definitely challenging, grew me as a parent. Now I know the meaning of "it takes a village" to raise kids. We are ever so grateful for our village; the heroes and angels watching over Jeremy. Family, friends, faith. Coaches, school counselors and teachers, our medical support team. Indeed, it takes a village.

Author Maisie Wong-Paredes is a NEA Ambassador.



FEATURE

You Want a Dog. Someone in Your Home Has Eczema. What Do You Do?

By Ilka Pinheiro

Choosing the right dog is tricky for families with eczema. But with the right evidence-backed guidance, there's a good chance you can find a pup that works with your family's potential allergies and skin care needs.

What is the risk of getting a dog if your family lives with eczema?

All dogs – regardless of the breed – have the potential to trigger your allergies and eczema.

According to Dr. Ari Zelig, a board-certified allergist in Germantown, TN, allergies are generally caused by exposure to dander (shedding flakes of dead skin). "Common symptoms of a canine allergy," Dr. Zelig said, "include itchy eyes, nasal congestion, sneezing and runny nose. It's important to note that environmental allergens such as dog dander can worsen eczema and can penetrate an impaired skin barrier, leading to further inflammation."

What about those so-called hypoallergenic breeds? Nick Miller is a Boston-based dog trainer and founder of Walden Dog Training; he often fields questions from clients with individualized healthcare needs.

"For families concerned about allergies, dogs with longer-haired coats are less prone to shedding, and therefore tend to be the best

option," Miller said. "These dogs usually have less dander that cause issues for people with skin conditions."

Before making the decision to bring a dog into your home, Dr. Zelig emphasized the importance of understanding the potential severity of canine allergies. "Highly allergic patients," he said, "may break out in hives if they come in contact with certain dogs."

When families with allergies ask about specific breeds, Miller said he usually recommends Portuguese Water Dogs, Soft-coated Wheaten Terriers and all three sizes of poodles and schnauzers.

How can you determine if someone is allergic to dogs?

A skin test or a blood test can reveal the exact nature of a potential canine allergy. Dr. Anna Fishbein, associate professor of allergy and immunology at Northwestern University, recommended patch testing for any family with eczema before bringing home a dog. She explained that the severity of an allergic reaction can be measured in a laboratory setting.

"We test by aerosolizing the allergen into the lung or nose at different quantities to see how much you need to react and how severe the reaction is," Dr. Fishbein said. "Most patients often know where they fall in that range [of allergic reactions], but certain dogs (not breed-specific) can be more allergenic than others. And meeting with an allergist is the best way to get to the bottom of this."

Before finalizing any decision, Dr. Zelig advised prospective dog owners to "spend time around a variety of dogs to make sure they don't provoke any allergy issues."

"There is no breed that is consistently eczema-friendly. The concept of a hypoallergenic dog is not based on research. There are different allergens produced by different dogs and these 'components' can be tested for with your allergist."

~ Dr. Fishbein

You've finished allergy testing and now you're ready to get a dog – for real

If you've completed allergy testing, talked to your healthcare team and you've picked out a dog, the next step is training the dog to minimize your risk of allergic reaction in your home. For many new dog owners with eczema, this means separating parts of your home into allergy-free zones.



"All dogs must learn basic rules, limits and boundaries when introduced to a new home," Miller said. "I would recommend that an adult keep a new dog near them using a leash to interrupt behaviors they don't want to see (such as jumping up on furniture). It is also helpful to have high-value treats to reward them when they get off the areas humans might not want them to go."

Miller explained that establishing "dog-free" rooms in the house could help minimize your exposure to the dog's dander. "Good dog training isn't rocket science," he said. "Set your dog up for success by introducing predictable routines and sensible household rules. Don't give them too much independence or responsibility before they can handle it. The dog you praise is the dog you'll see more of over time."

Your new dog follows all your rules, but you're still having allergic reactions

Part of the challenge in bringing home a dog is that your allergies may vary in severity over time.

Some people eventually experience fewer allergy symptoms and "get used to being around their dog," said Dr. Fishbein. "Other patients get more allergic and have severe, uncontrollable eczema or asthma, which then reverses when the dog is taken out of the home."

If your allergies get worse over time, Dr. Zelig suggested that "immunotherapy, also known as allergy shots, can help desensitize you and make you less allergic to your dog." Scheduling a follow up appointment with your allergist, after you bring a dog home, Dr. Zelig said, will give you an opportunity to review your skin care regimen and any medications that might help decrease or prevent your symptoms.

Wash your dog at least weekly, Miller said, and be sure that the person washing the dog is not the person who's allergic to the dog to avoid direct contact with any allergens.

"Dogs live in a human-dominated world," Miller said. "And they need your guidance to succeed in it." To facilitate your dog search, consider a visit to your local chapter of the Humane Society, which allows families to visit and play with canines who are candidates for potential adoption.

Mental Health and Children With Eczema

By Steve Nelson

In this edition of Ask the Ecz-perts, we discuss what parents might consider when deciding if their child with eczema would benefit from seeing a mental health professional. Studies show that children with eczema are much more likely to develop anxiety or depression and to experience lower self-esteem.

Our experts include: Lisa Lombard, PhD, a licensed clinical psychologist who practices in Chicago; Jennifer Moyer Darr, LCSW, a licensed social worker with the National Jewish Health organization; and Morgan Maier, PA-C, a dermatology physician assistant at Seattle Children's Hospital.

For a young person with moderate to severe eczema, what are the benefits of talking to a therapist?

Jennifer Moyer Darr, LCSW (JMD): Sometimes just having a safe place to share your feelings is enough. Normalizing a child's emotions and experiences is immensely helpful. Learning to relax and calm your body can help kids with eczema decrease their itching. For older children, we often focus on issues related to relationships, individuation and taking on responsibility for their own healthcare needs. We also work on building their self-esteem.

Lisa Lombard, PhD (LL): Talking with a therapist can help a young person build coping skills for managing stress and anxiety. This can also really improve sleep. Some therapists may also use role-playing to practice social scenarios where the child may often receive blunt or hurtful comments from other children; this can help the child feel more comfortable in social situations like school, sports and parties.

Morgan Maier, PA-C (MM): Having someone to talk to – who isn't a parent or guardian, or even a friend – is helpful because it creates a safe space: there may be a social dynamic with the parent that prevents the child from being forthcoming about their own concerns and issues with atopic dermatitis (AD). In that safe space, the child can discuss with the therapist how AD is impacting their life.

What are some indications that a child with eczema might benefit from mental health counseling?

JMD: It's not unusual to see increased anxiety and depression in children with eczema – especially when it is moderate to severe. Pay attention to whether your child is withdrawing from friends and activities, talking negatively about themselves or expressing anger at their illness.

Passive suicidal ideation is scary and not uncommon, but this is a mental health symptom that needs intervention. Passive suicidal ideation is thinking about dying or a desire to be dead, without a plan or intent to act on it. Comments such as "my life would be easier if I were dead" can show how overwhelmed and sad some children become when managing their healthcare needs. If a child or loved one ever has active suicidal ideation, this requires immediate attention. Call 911 or your nearest emergency room.

LL: Parents need to consider whether their child's behavior is interfering with their daily functioning. If your child is demonstrating any of the following, it's a good indication that they need some degree of mental health support:

- Isolation (and used to be more social);
- Irritability and negativity (compared to neutral to positive mood);
- Unexpectedly crying and tearful;
- Sleep problems;
- Quick to anger in ways that are excessive and even destructive;
- Unexplained decline in school work;
- Regression, i.e., behaving in ways more typical of when they were younger;
- Self-harming; or
- Expressing hopelessness.

What questions should parents be asking themselves to better understand their children's mental health as they enter the "tween" or teenage years?

MM: As kids get older, it can be harder to connect and figure out how they're doing for a wide variety of reasons, including the typical tween/teen desire for autonomy. For parents of tweens/teens who live with eczema, ask yourself the following questions:

- Are they participating in the activities they normally like, such as sports, art, hanging out with friends?
- Do they mention or point out when they see someone with good skin?

- Do they keep their skin covered even in warmer weather?
- Do teachers express concern about your child sleeping in class, itching in class, having outbursts or withdrawal from social interactions?
- Are they searching the Internet for solutions for their skin?
- Are they displaying signs of stress and anxiety like picking at the skin, pulling at their hair or other hygiene changes?

Having a safe place to have a sounding board, where there is no judgment, is essential and can also help young patients with motivation, stress reduction techniques, goal building and other tools to help young people be successful in treating their eczema.

Is family therapy a good option?

JMD: Family therapy helps everyone understand each other more effectively. Sometimes it's easier when we have a neutral party to help parents figure out what drives certain behaviors. And don't forget to involve siblings: they often have their own feelings about how one child's eczema impacts the whole family's dynamics.

LL: Family therapy helps parents express support, concern and share difficult feelings. I would emphasize a team mindset and talk about how parents are "coaches" to support and encourage children to make lifestyle changes that can reduce their flare ups. For younger children, it could be the sole method of treatment. For tweens and adolescents, family therapy is a good idea on an intermittent basis to complement individual therapy sessions.

What should a parent consider when looking for a therapist for their child?

JMD: Finding a therapist with eczema experience is ideal. Ask your eczema provider for recommendations, as they may know people in the healthcare community. Finding a provider who at least understands and works with chronic health conditions is your next best option; still, you may have to provide them with some education specific to your child's healthcare issues. You'll also want to consider providers who are in network with your insurance. Not all plans have mental health coverage, but depending on the plan, and the individual's needs, therapy can sometimes be billed as what's referred to as a "Health and Behavior Code."

LL: Look for someone who is a licensed clinical practitioner. The younger the child, the more important it is for the parents to be involved, too. Some children, tweens and older, may appreciate a therapy group with their peers, as they would be able to see that other teenagers their age experience similar emotions.

MM: Many practices now have screening questions to help ensure that a child and therapist are a good fit. Parents should consider what they can fit in their child's schedule. Is video therapy easier or is it preferable to meet in person? Does the family prefer a provider with experience in the LGBTQ+ community? Does the age or ethnicity of the provider matter to the family? Having a therapist that fits with what the family feels most comfortable with is very important.

What if your child is reluctant to see a therapist?

MM: If your child is reluctant to see a therapist, encourage an honest conversation. Ask them questions about why they don't want to go. What are their fears about therapy? Is there a stigma? Acknowledge with your child that it can feel weird or foreign to talk to a stranger about personal issues and that it's normal to take it slow until they gain trust with the therapist. It's okay that the child may not want to really open up right away, that it takes time.

JMD: I sometimes tell parents: "you may be able to force them into the car, but you can't force them to talk." Many children don't want to talk or scowl at us through their first session. Often children don't understand the concept of therapy and view it as a consequence to something they did or something about them. Try talking through the benefits of therapy. Agree to a set number of sessions. Let the therapist know about your child's reluctance in advance of the meeting and share some suggestions about what may help your child feel more relaxed in the meeting.

Do you have a question for our ecz-perts? Email them to Editor@NationalEczema.org.

MEET THE ECZ-PERTS



Lisa Lombard, PhD
Lisa Lombard, PhD is a licensed clinical psychologist who practices in Chicago.



Jennifer Moyer Darr, LCSW
Jennifer Moyer Darr, LCSW, is a licensed social worker with the National Jewish Health organization.



Morgan Maier, PA-C
Morgan Maier, PA-C is a dermatology physician assistant at Seattle Children's Hospital.

NEA's New Study Finds Shared Decision Making Beneficial in Care of Patients with Eczema

To what extent do patients with eczema provide input into their own treatment and what factors contribute to positive care conversations?

The National Eczema Association (NEA) research team sought to answer these questions in their latest publication based on survey findings from eczema patients and caregivers. Published July 6, 2022 in JAMA Dermatology, this paper discussed the eczema community's experiences with shared decision making, a practice that can contribute to desired care outcomes.

FROM THE SURVEY RESULTS OF
1,313 →
PATIENTS AND CAREGIVERS

Investigators found a "higher degree of involvement in shared decision making was significantly associated with higher consultation satisfaction."

Motivating factors found to increase participation in shared decision making include:



The clinician welcomes the patient's input or initiates an opportunity for shared decision making;



The clinician acknowledges the patient is the expert on their body;



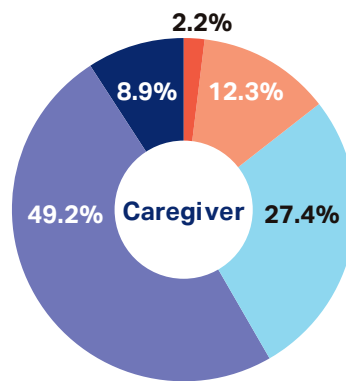
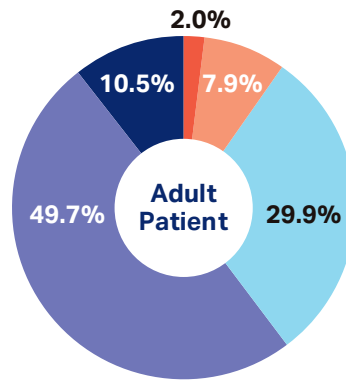
The clinician provides multiple recommendations for treatment and helps guide the patient toward a decision;



If treatment is or is not working.

Nearly 50% of respondents state they prefer to make their own decision after considering the doctor's opinion.

- I prefer for my doctor to make the decision.
- I prefer that my doctor makes the decision after seriously considering my opinion.
- I prefer that my doctor and I share the responsibility for the decision.
- I prefer to make the final decision after seriously considering my doctor's opinion.
- I prefer to make the final decision.



69.4% of respondents felt very or extremely confident to engage in shared decision making in the future.

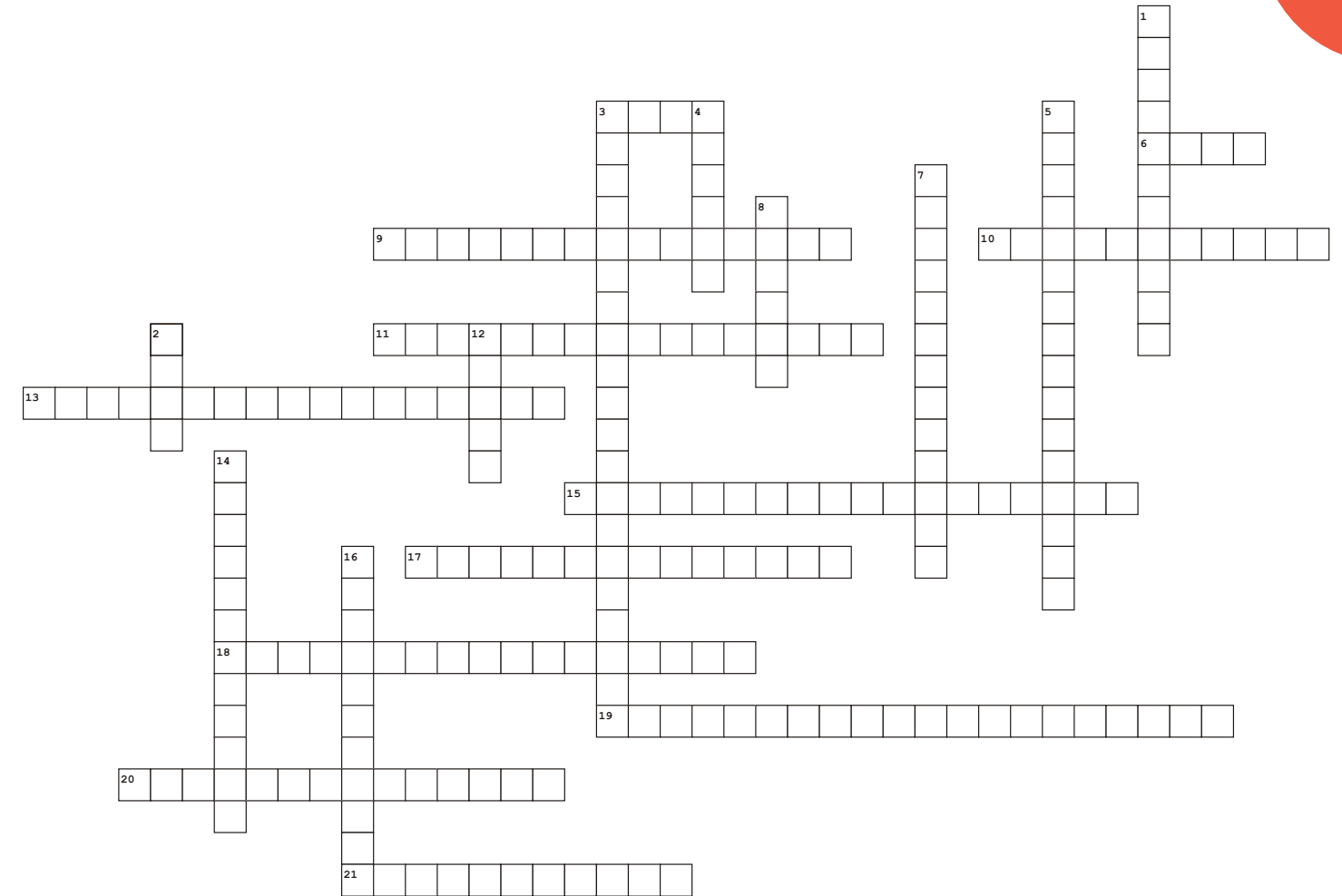


Those who reported feeling "very well informed" about eczema causes were **3.4 times more likely** to be confident to engage in future shared decision making.

Thibau, I.J., Loisel, A., Begolka, W.S. et al. Past, Present, and Future Shared Decision-making Behavior Among Patients With Eczema and Caregivers. *JAMA Dermatol* (2022).

The NEA Crossword Puzzle

Good luck on our fall NEA Crossword Puzzle. Let us know if you think it's too easy, too hard or just right! Answers are available online at NationalEczema.org/Fall22-Crossword or scan the QR code.



ACROSS

3. The human body's largest organ.
6. Near universal symptom of eczema.
9. Also called discoid eczema, this condition affects small patches of skin and makes them itchy and scaly.
10. Body's first line of defense against external irritants and allergens.
11. A skin discoloration on the legs which looks similar to varicose veins.
13. This type of eczema dries out the skin and can cause a burning sensation, rashes and blisters.
15. In which your healthcare provider must get approval from your insurance company before prescribing a particular medication.
17. Also called nummular dermatitis, this form creates small, rounded lesions all over.
18. This form of eczema is brought on by environmental triggers.

19. The process of a healthcare provider working with a patient or caregiver about medically appropriate treatment options.
20. Location where NEA was originally founded.
21. Also known as "fail first," requiring a patient to try and fail another (usually less expensive) drug before an insurance company will cover the medication originally prescribed by the doctor.

DOWN

1. Phrase describing the progression of eczema leading to asthma and allergies.
2. This is a distinct burden in AD, separate from itch, and is a newer area of research.
3. An inflammatory form of eczema which appears on the body where there are lots of oil-producing (sebaceous) glands like the upper back, nose and scalp.
4. Location of NEA's headquarters in California.
5. The most common form of eczema which causes inflammation, dryness and itchy skin.
7. Essential part of new drug development.
8. Describes an allergy in which a hypersensitivity reaction may occur in a part of the body not in contact with the allergen.
12. People with eczema and caregivers of someone with eczema often find this disrupted.
14. Series of games to engage families and researchers around management of childhood eczema.
16. Volunteer NEA program making a difference in advocacy, research and community outreach.



This October,
**Let's Focus
on Eczema**

Join us for Eczema Awareness
Month. Learn more and get
involved at [EczemaMonth.org](https://www.EczemaMonth.org).
