National
Eczema
Association

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NEA Magazine

Research, Support and Education for Those Affected by Eczema

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Spring 2023 **NationalEczema.org**

NEA Magazine

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Eczema By the Numbers: Shared Decision Making

New NEA research breaks down the essential elements of shared decision making and how it's more likely to be facilitated between empowered patients and healthcare providers.

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 treatments should consult a professional healthcare provider. Opinions expressed by NEA Magazine do not necessarily reflect the views of the National Eczema Association, its Board of Directors, its Scientific & Medical Advisory Council or its contributors.

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International Alliance of Dermatology Patient Organizations

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Letter from Julie

Happy spring to all! As the days grow longer, so does my list of reasons to look forward to a season of new growth, beginnings and connection.

Since our last issue, we've already had a lot to celebrate. This year marks the 20th anniversary of our Research Grants program. We are doubly thrilled by this milestone since it also marks the highest amount of funds we've ever been able to dedicate to eczema research — a total of $1 million! We truly could not do it without you. Applications are currently open, and you can read more about it on page 3.

Looking ahead, Eczema Expo 2023 is right around the corner! This year's NEA family vacation will be one for the books, taking place June 22–25 in Orlando, FL. For me, personally, Expo is always one of the highlights of my year, and I'm so looking forward to reuniting with you all in person for some fun in the sun. See our back cover for registration details!

In the meantime, we're sharing the latest developments in seborrheic dermatitis research on page 8, an area rich in advancing science and promising developments. Additionally, the NEA research team recently published its latest paper on shared decision making between patients and/or caregivers and healthcare providers. Check out their findings on page 28.

On page 17, you'll find a history of eczema through the ages to help visualize how we grow through the challenges we go through. We've come a long way since the first suspected eczema remedies — some of which may surprise you!

Finally, we're excited to feature more of your voices throughout this issue, including original artwork from our community on page 14. It's truly moving to see your stories come to life visually, especially at a time when new beauty is blooming all around us.

As always, we're wishing you warmth and good health this spring from all of us here at NEA.

With gratitude,

Julie Block

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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National
Eczema
Association

NEA NEWS

Eczema Expo 2023, S'more Time with the Doc, Research Grants and Itching for a Cure

Eczema Expo 2023

For Eczema Expo 2023, we're gathering our entire eczema family together — uniting people who have eczema, their caregivers, healthcare professionals and industry ecz-perts — for four days of education, support, connection and family fun. Load up the minivan and claim the front seat now, because this family vacation will be one for the books. Whether you're the type of vacationer who likes to unpack and unwind, get out and explore or all of the above, we've got you covered:

- Temperature-controlled, fragrance-free rooms and allergen-conscious menus
- Empowering, informative discussion and panel sessions with world-class medical professionals
- Fitness and social activities for all ages where you'll meet new friends and let loose
- Support sessions where you'll give and gain advice about life with eczema with people who get it

Register today at **EczemaExpo.org**!

Introducing S'more Time with the Doc

Our latest video series is here! Launched last month, S'More Time with the Doc features four pairings of an eczema patient or caregiver with a healthcare provider. The pairs sit in front of a fire making s'mores while they discuss the patient-doctor dynamic, its pitfalls and opportunities. The casual, open-ended format allows for conversations that never happen in the doctor's office. Check it out at **NationalEczema.org/smore-time-with-the-doc**.

20 years of NEA's Research Grants

2023 marks the 20th anniversary of NEA's Research Grants program. Since its first grant was awarded in 2004, NEA has aimed to fill a critical gap in eczema research, to increase the number of scientists, research projects and dollars devoted to eczema research which will lead to better therapies, better care, better outcomes — and one day, potentially a cure.

Most notably, for every $1 NEA has invested in eczema research, grantees have collectively gone on to obtain an additional $10.12 in subsequent National Institutes of Health (NIH) funding to support further eczema research.

This year for the first time NEA will award a total of $1 million to investigators of all levels and across categories. Applications are currently being accepted and must be received by July 31, 2023, at 5 p.m. PDT. Recipients will be announced in November 2023.

Are you Itching for a Cure?

Register today to raise funds to help end eczema.

Eczema champion ecz-traordinaire, Dr. Peter Lio, is challenging you to raise funds for eczema research — and he is matching the first $30,000 raised in May!

Join Itching for a Cure by registering, setting your fundraising goal and picking your favorite fundraiser — a walk, a party, a bowling night, an online fundraising drive ... the possibilities are endless! Register at **Donate.NationalEczema.org/IFAC2023**.

NEA Ambassadors' Corner

NEA Ambassadors can check another accomplishment off their list.

Since early 2022 NEA Ambassadors have been advocating with various congressional members (including sharing their personal stories as part of Virtual Hill Day last June) to elevate awareness of and investment in eczema.

One priority was to ensure eczema would be added as an eligible condition for research funding through the Department of Defense (DOD) Peer Reviewed Medical Research Program (PRMRP) as FY23 appropriations were finalized.

As a direct result, eczema has been added to the FY23 appropriations. This means, for the first time, eczema researchers can submit projects for DOD funding. Want to get involved in future advocacy efforts? Become a NEA Ambassador today! Learn more at **NationalEczema.org/Ambassadors**

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National Eczema Association

WITH DUPIXENT,
I'M STAYING AHEAD OF MY ECZEMA.

Help heal your skin from within, with DUPIXENT, a breakthrough eczema treatment. DUPIXENT helps block a key source of inflammation inside the body that can lead to uncontrolled moderate-to-severe eczema (atopic dermatitis).

Available for children 6 months of age and older.

HELP HEAL YOUR SKIN FROM WITHIN™

- Fast itch relief*
- Clearer skin that lasts**
- Not a steroid or immunosuppressant

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

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

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(dupilumab) Injection
200mg · 300mg

TALK TO YOUR ECZEMA SPECIALIST & LEARN MORE AT DUPIXENT.COM

Today's a good day to find out if DUPIXENT, a biologic, could be right for you.

INDICATION

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

IMPORTANT SAFETY INFORMATION

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

Before using DUPIXENT, tell your healthcare provider about all your medical conditions, including if you: have eye problems; have a parasitic (helminth) infection; are scheduled to receive any vaccinations. You should not receive a "live vaccine" right before and during treatment with DUPIXENT; are pregnant or plan to become pregnant. It is not known whether DUPIXENT will harm your unborn baby. A pregnancy registry for women who take DUPIXENT during pregnancy collects information about the health of you and your baby. To enroll or get more information call 1-877-311-8972 or go to https://mothertobaby.org/ongoing-study/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. DUPIXENT can cause allergic reactions that can sometimes be severe. Stop using DUPIXENT and tell your healthcare provider or get emergency help right away if you get any of the following signs or symptoms: breathing problems or wheezing, swelling of the face, lips, mouth, tongue, or throat, fainting, dizziness, feeling lightheaded, fast pulse, fever, hives, joint pain, general ill feeling, itching, skin rash, swollen lymph nodes, nausea or vomiting, or cramps in your stomach-area.

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

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

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

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

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

Please see Brief Summary on next page.

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DUP.22.11.0161

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

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

What is DUPIXENT?

- DUPIXENT is a prescription medicine used:
  - to treat adults and children 6 months of age and older with moderate-to-severe eczema (atopic dermatitis or AD) that is not well controlled with prescription therapies used on the skin (topical), or who cannot use topical therapies. DUPIXENT can be used with or without topical corticosteroids.
- 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 2 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 6 months to less 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 eczema 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.

How should I store DUPIXENT?

- Store DUPIXENT in the refrigerator at 36ºF to 46ºF (2ºC to 8ºC).
- Store DUPIXENT in the original carton to protect from light.
- DUPIXENT can be stored at room temperature up to 77°F (25°C) up to 14 days. Throw away (dispose of) any DUPIXENT that has been left at room temperature for longer than 14 days.
- **Do not** heat or put DUPIXENT into direct sunlight.
- **Do not** freeze. **Do not** shake.

Keep DUPIXENT and all medicines out of the reach of children.

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
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HEARD ON THE STREET

What Guilty Pleasures are You Not Willing to Give Up for Your Eczema?

We asked and you answered: *What guilty pleasures are you not willing to give up for your eczema?*

Ice cream
@Mrclean_onthefly

Petting cats 🐱 and dogs 🐶. Enjoying citrus foods and drinks 🍋🍊
@Yaekak

Hot baths
@sofiesamara

The one fried egg i eat once a year 😍
@hana.ferdous

Fragrance! Scented candles!! 💓
@pcervini

Surfing and gardening (esp. on a hot day)
@tess_tickle69

🧀🧀🧀🧀
@j0j0grams

My dog 🐶❤️ She's my rock but I only found out I was allergic with skin prick testing. She's never leaving my side. I'll be itchy.
@judy_cakes_

My dog
@klilacjw

My dog Walter ❤️ Happy to give up the polishing and vacuuming though! The dust makes me so itchy!👍
@lifeatpeartreefarm

Oranges 🍊😍
@sini_kettu

I'm with everyone on the hot showers, and sugar
@_bna

Chocolate
@katederanleau

Alcohol — the pain isn't severe enough to warrant the ban of cocktails or gin and tonics forever!
@Love_theskin_imin

DEFINITELY HOT SHOWERS AND CHEEEEEEEEESE
@iamzoara

Bleaching and coloring my hair, and of course the steaming hot showers 😂
@emma.gropendahl

Cheese/pretty much any food product
@emilylt03

HOT SHOWERS! I choose the mental relaxation benefits over its adverse effects on eczema... besides, less stress means less eczema for me!
@kaehlamaurer

30 seconds of hot showers and the occasional long, hot bath ✨
@therealeliselee

Fleece tracksuits & hot baths ❤️
@sarahgibbsxoxo

Dairy and cuddling cats and dogs!
@hannahashum

Coffee and chocolate
@micadejesus_

Long hot relaxing bubble baths
@not_a_dermatologist

Chocolate
@aila17

Hot showers & sugarrrrr
@tedgi2

RESEARCH

SEBORRHEIC DERMATITIS —

What the latest research is saying, from how it develops to current treatments and more

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

Dandruff and cradle cap — these are terms you have likely heard before. Medically, they are part of seborrheic dermatitis (SD), one of the seven forms of eczema. SD is a common, chronic, relapsing form of eczema that typically affects the face and scalp but can appear in oily skin elsewhere on the body (including ears, H-zone of the face, central chest, areas with dense body hair, etc.). Common symptoms include flaking skin with visible skin inflammation, dandruff, patchy or flaky white or yellow scales on top of greasy skin, rash (sometimes ring-shaped) and itch.

To date there is little research about the underlying causes of SD, but contributors include colonization of skin with a yeast called *Malassezia* and changes in a person's immunity, skin barrier and sebaceous gland function (glands near hair follicles that secrete oil to lubricate hair and skin).[1] Treatment options for SD include both over-the-counter approaches as well as topical drugs that have been approved for treating other diseases like psoriasis or atopic dermatitis (AD).[2] In more severe and stubborn cases, oral medications may be used. While few treatments have been studied specifically for SD, a potential new topical therapy is on the horizon.

OCCURRENCE AND APPEARANCE OF SD IN VARIOUS POPULATIONS

SD has been reported to exhibit peak incidence in three age groups: infancy within the first year, adolescence and young adults when sebaceous glands are changing during and after puberty and again between 30 and 60 years of age.[1,2] During infancy, SD is often transient and known as "cradle cap", appearing mostly on the scalp with yellowish, crusty lesions. In adolescents and adults, SD can become more persistent and appear as yellow, greasy, adherent scales with reddened skin on the scalp, face, ears and upper chest.[1] The lesions can also be itchy. Dandruff, or flaking without visible skin inflammation, is thought to be present in between 15% and 50% of affected individuals.[1] The global prevalence of SD is generally estimated to be about 3–5%, although this number may be affected by differences in rates of recognition and diagnosis. The burden of SD in different parts of the world was also recently reported with higher prevalence in Sub-Saharan Africa and North America, particularly the United States, and lower prevalence in Central Asia and Eastern Europe.[3] The differences in SD incidence between geographic regions may be attributed to skin type, the type of *Malassezia* species present in the region and how the climate impacts the microbiome.[2]

The incidence of SD is higher in immunocompromised patients and patients with skin of color with incidence of 6.5% in African Americans.[4]

> *SD is one of the top five most common skin conditions in African Americans, but not white, Asian, or Hispanic populations.[2] Misdiagnosis or delayed diagnosis of patients with skin of color can happen frequently.[4]*

Changes in pigmentation, such as loss of color in the area (hypopigmentation), may be one SD symptom in patients with skin of color. As with other skin diseases that have been characterized by "redness" on white skin, SD may appear tan, gray or purplish on darker skin.[5]

A few studies have highlighted the coexistence of SD with other skin conditions and other eczemas. For example, patients with SD have been reported to have lower incidence of allergy-induced contact dermatitis, but SD patients were often diagnosed as having contact dermatitis.[6] Researchers discovered that the allergens underlying SD varied from those underlying contact dermatitis.[6] Several reports helped explain to physicians how to differentially diagnose SD as opposed to other diseases including psoriasis[7] and more rare skin disorders including pemphigus foliaceus.[2] AD and SD are both prevalent in infants and can co-occur, particularly on the face and scalp, often making them difficult to distinguish from each other in infancy.[8] Compared to SD, infants with AD are characterized by lack of sleep. Additionally, SD of infancy typically resolves before two years of age while AD can persist.

CAUSES OF SD

MALASSEZIA

Colonization of skin with the yeast-type of fungus *Malassezia* has been the most attributed cause of SD, but other factors such as sebaceous gland activity, underlying genetics, immune factors, hormones and other components of the microbiome likely also play a role.[9] No one knows exactly why *Malassezia* colonization contributes to SD, but sebum, the substance produced by sebaceous glands to moisten skin and hair, is one source of food for *Malassezia*. It may be that increased sebum production leads to an environmental advantage in which *Malassezia* can thrive. Immunocompromised individuals can struggle with increased colonization with *Malassezia* and therefore increased incidence of SD. For example, 40% of patients infected with HIV have SD while 3–5% of the general public have SD.[3,10] Immunosuppression-using medication, for example after organ transplantation, can also be associated with higher incidences of SD.[1] The fact that treatment with either antifungals or with topical steroids that modify the immune system work to treat SD means that certainly *Malassezia* is not the only factor contributing to SD pathology.[1]

The complex causes of SD have not been easy to study. Dr. Benjamin Ungar of Mount Sinai Hospital and Medical School said, "In order to understand the pathophysiology of SD, skin tissue sampling from patients with SD is needed to allow for molecular studies, similar to other inflammatory skin diseases. With the typical distribution of SD involving the face and scalp, this has historically been a challenge. The current understanding of molecular underpinnings of SD has been limited to only a few small studies."

GENETICS AND IMMUNE INVOLVEMENT

Research investigating the genetic contributors to SD has been very limited. A few mouse models have been developed that exhibit SD-like symptoms so that genetics and other underlying factors, such as immunologic factors, that contribute to disease can be studied.[11-13] Genetic studies using these mouse models as well as human samples have identified around 11 genes that can be mutated in SD including five genes that control different components of the immune system and two genes that are important for skin cells to differentiate and create the barrier function of the skin.[14] Mice missing one of these barrier genes, called Myelin Protein Zero Like 3 (MPZL3), developed SD-like features spontaneously without being immunocompromised.[12] This model also revealed changes in the immune system including greater presence of immune cells in the mouse skin, linking the

3D illustration of *Malassezia*

importance of the immune system and the skin barrier for development of SD. Further study of this model revealed that the cytokine (immune cell messenger) interleukin (IL)-17 was increased in SD-like mice, helping point the way toward a deeper understanding of which immune cells (T cells) may be involved in SD pathology.[13]

In addition to IL-17 increase found in the SD-like mouse model, a large number of inflammatory markers are increased in SD, including several other cytokines (IL-1α, IL-1β, IL-2, IL-4, IL-6, IL-8, IL-10, IL-12) and other immune stimulators (TNF-α, beta-defensins, IFN-γ, nitric oxide and histamine).[15] An immune response against *Malassezia* yeast on the skin is also thought to play a part in pathology.[15]

MICROBIOME

The microbiome (the spectrum of living organisms like bacteria, fungi and other species that live on skin) differs in SD skin beyond just the expansion of *Malassezia*.[16] Again, only a few studies have been done, but several changes in bacterial levels on the skin and the balance between bacterial types were found in SD patients compared to those without SD.[15] Environmental influences like hot or cold weather and hormone differences, such as between males and females, may alter *Malassezia* and other components of the microbiome. Diet, use of certain skin care products and growth of facial hair could also be a factor, although research is still needed to link these factors with microbiome changes.[2] Some research is currently focusing on modulation of the microbiome using medication or over-the-counter (OTC) approaches. OTC probiotics may be useful for improving symptoms associated with SD.[17] Certain species of bacteria are sensitive to topical ketoconazole, which is commonly used to treat SD. Another drug taken systemically, itraconazole, can reduce *Malassezia* and may have an impact on other components of the microbiome.[16]

TREATMENT APPROACHES

Current treatment approaches for SD may vary considerably depending on the age of the individual and co-occurring diseases they may have. Treatments for infants and for adults with mild SD currently range from special OTC or prescription shampoos to creams, to topical antifungals and topical steroids, but there is not one uniform approach to SD treatment.[18,19] Infants are generally treated with OTC baby shampoos enriched with emollients (shea butter, glycerin) or vegetable oils.[9] Most adolescents and adults with SD are treated with a multipronged approach that can involve topical or systemic treatments.[18] Dr. Andrew Blauvelt, MBA of the Oregon Medical Research Center said, "What has happened in the past is that topical drugs approved for other conditions like psoriasis or AD have been repurposed for treating SD." Indeed, topical corticosteroids and calcineurin inhibitors, both of which alter immune reactions, have been used to treat AD and SD.

Ketocoazole was introduced in 1979 as a systemic compound with activity against fungi through disrupting formation of fungal cell membranes. A topical form of ketoconazole 2% was FDA approved in 1990 as a prescription shampoo for scalp SD in patients 12 and over. In 1997 it was approved as an OTC 1% shampoo for dandruff or flaking scalp.[9] Creams or gels containing ketoconazole were approved for treating other body sites in 2002 and 2006.[9]

Treating SD in patients with skin of color can also be challenging. Dr. Susan Taylor of the University of Pennsylvania said, "Scalp SD in these patients cannot be treated with prescription shampoos because they are very drying for tightly coiled hair, which leads to breakage. Education of healthcare providers on the presentation of SD in diverse populations and on hair care practices and customs may serve to improve outcomes for patients with skin of color."

While there are currently limited treatment options for SD management, Dr. Blauvelt recently presented the results of a Phase III clinical trial (a step before the end of the process of seeking FDA approval for use of a specific drug to treat a specific disease) for a topical drug called roflumilast, which was already approved for psoriasis treatment. Dr. Blauvelt said, "80% of patients with moderate-to-severe SD treated with roflumilast foam experienced clearing (50% of treated patients) or partial clearing of their disease after 8 weeks of once daily applications. Study participants were extremely satisfied with the results. Studies of SD have been rare, even though the disease is very common, and most of the current therapies have drawbacks that can limit their use, so I think this new treatment is going to be very important for SD patients if it gets approved."

Articles have called for both additional research into drug development and collaboration between patients and medical providers to determine the most appropriate treatment approaches for SD.[18,19] It is important for affected individuals to be aware that SD can go away and come back again and that treatment may need to be long term, particularly in adolescents and adults.

UNMET NEEDS AND FUTURE DIRECTIONS

Future studies are needed to understand wider factors underlying SD. Several articles have recently highlighted the higher percentage of patients with SD in African Americans compared to white individuals, meaning that the burden of this skin disease is higher in this population. Studies are needed to understand why this health disparity exists and if existing treatments, often borrowed from other diseases, are effective in diverse populations.

Recently SD has gained interest in the research community since receiving attention in the mainstream media. Masks worn to avoid COVID-19 illness were associated with an increase in SD incidence.[2] Dr. Taylor said, "I believe that when attention is given to any disease entity, it sparks interest regarding research and development of agents to address the disease. Pharmaceutical companies are always searching for unmet needs in medicine and articles and news segments highlight unmet therapeutic needs in diseases that they may not be aware of."

Overall, this is an exciting period in history for understudied skin diseases as there are new, noninvasive skin sampling techniques and new technologies that allow characterization of all the cells playing roles in a specific disease.

> *With revolutionary new treatments occurring for multiple skin diseases, this common form of eczema may be getting some long overdue attention, as well as much needed research and treatment options.*

Dr. Benjamin Ungar, in addition to providing insight into why SD has been so difficult to study, also provided great optimism for the future. He said, "This is a very exciting time for research in SD, because newly developed minimally invasive skin sampling techniques now offer the ability to collect samples from large numbers of patients without biopsies that leave scars, enabling gene and protein expression studies. Furthermore, with new non-steroidal treatments for SD on the horizon, there is an opportunity not only to characterize the SD disease state itself, but also to tease out the immune pathways that are modulated with different treatments that lead to clinical responses. Huge advances will be made in understanding SD pathogenesis in the upcoming months and years."

TAKE HOME POINTS:

- SD appears predominantly on the scalp and face, and it is understudied compared to other skin conditions.
- Underlying causes of SD include colonization of the skin with *Malassezia* as well as changes in the skin barrier and immune system. Only a few genetic studies have been performed.
- Ketoconazole is FDA approved for the treatment of SD, but understanding more about the disease will lead to better treatment approaches.
- A new topical treatment for SD (roflumilast) has completed Phase III clinical trials and will be evaluated for approval by the FDA in the near future.

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COMMUNITY POV

Finding Joy in Vulnerability:

What I learned from my mental and emotional trauma journey living with eczema

By Gregg Clark Jr.

When I first think of eczema, I think of a physical skin condition, as I am sure many of us do. Even though people with eczema are impacted both physically and mentally, we tend to keep focus on its physical ailments, as opposed to how much we have suppressed mentally and emotionally from the trauma of eczema. That being said, it fills my heart with joy to share both who and what are supporting me through the trauma from my eczema journey in the hope that it may help you on your journey, too.

Recognizing what trauma can look like

Severe eczema and topical steroid withdrawal (TSW) symptoms left me on bedrest for six months. Another word for bedrest, looking back at my journey, is isolation. I felt alone in a variety of ways: having to explain to those close to me what I am dealing with, forcing myself into isolation with shame and embarrassment for how I looked and the burden I felt I put on people when they simply asked, "How can I help?"

AD is the **leading contributor to skin-related disability** and **ranks 15th among all non-fatal diseases globally.**[1]

One-third to one-half of adults with AD avoid social interactions because of their appearance.[2–4]

As a man who has had much success in athletics, it came naturally for me to live life through a masculine mask. I remember hearing "Don't show emotion," "Play through the pain," or even, "That's for girls" as a young boy. These negative affirmations subconsciously taught me how to suppress my true feelings and emotions, and at times of trauma I was unable to express my basic needs to others.

Pre-adolescent girls with AD more frequently report impaired self-perceived health than pre-adolescent boys.[3–5]

AD's negative impact on mental health ranks greater than that for patients with heart disease, diabetes and high blood pressure.[6]

One may ask, 'How does sharing this bring you joy?' My answer is because I have built a foundation that supports me through the trauma of my eczema journey. Now, as a mental health professional, I support the patients and clients I get to work with by using that same foundation — and I am excited to share this with you, my NEA community:

1. Look beyond the loop

First things first, create a vision of what you want the rest of your life to look like. It's well-documented that the power of trauma can leave us in a negative loop cycle with repeated actions, emotions and behaviors reaffirming what we already believe about ourselves. In moments of pain, I thought, "I'll never get over this." Little did I know I was creating my own reality.

> I realized I could also create a detailed vision of what I wanted my future to look like by first gathering the vision and feeling in my mind and body.

2. Audit your environment

Second, create a supporting cast of people in your life. I began to audit my environment and removed those who literally made me feel sick. This initial realization allowed me to accept that I had previously allowed people in my life who did not serve my best interest. I was able to cultivate a group of people who help speak life into me and support my goals. Through meditation and prayer, I have come to understand that I do not have to be strong alone. In fact we are stronger when we are together.

Photo courtesy of Gregg Clark Jr.

3. Take action, and reality will catch up

Lastly, take action to bring your new vision of self to reality. Who we are being is who we are becoming. At first it felt like imposter syndrome, and sometimes it still does, but I began living my life as if I was the character I created in my vision for the future and continued to see my reality catch up. I slowly began changing the way I lived: first, by changing my mindset with a new vision and second, by finding people who support me through the dark times as well as help inspire me to bring my vision of self to reality.

"There is no hierarchy in healing; we heal simultaneously."

In my experience, there is no hierarchy in healing; we heal simultaneously. From our individual eczema journeys we can see there is no one-size-fits-all approach when it comes to what works for us. It's a subtle reminder to me that we're all made to live a customizable life and what once brought me shame is what now brings me joy.

Gregg Clark Jr. is a professional life coach and mentor.

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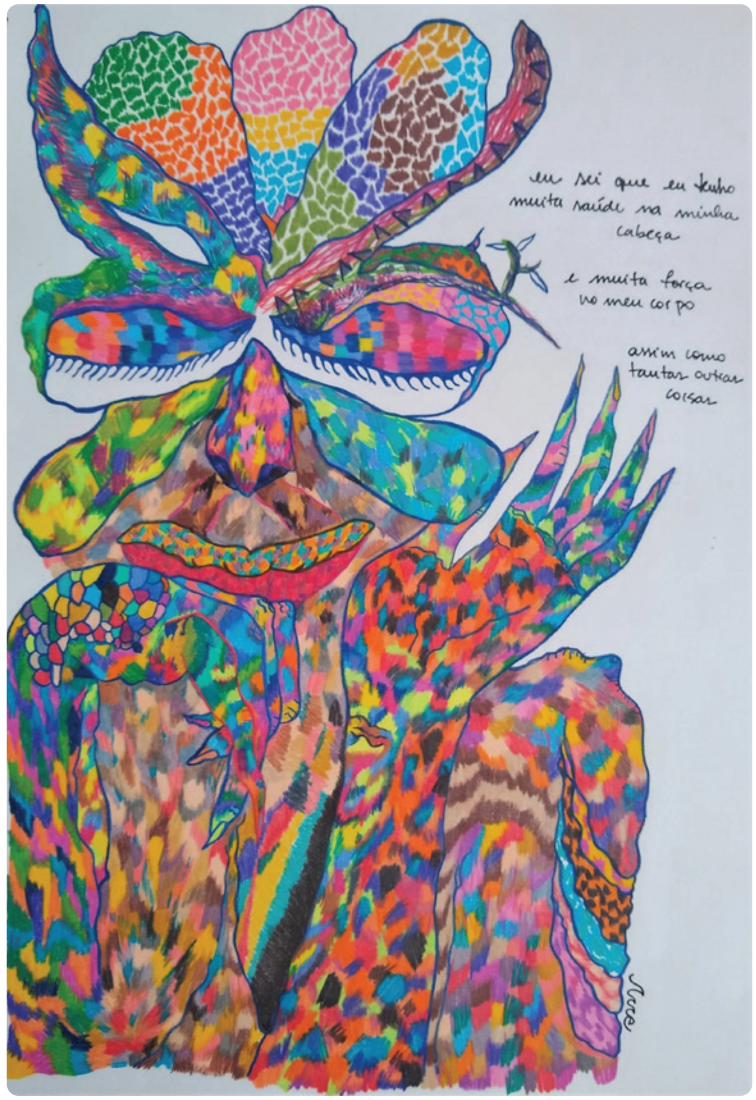
NEA ARTISTS

Original Artwork From Our NEA Community

We have an open call for the community to share original artwork in these pages and we always love seeing your creative expression.
To submit your work for an upcoming issue, email editor@nationaleczema.org.

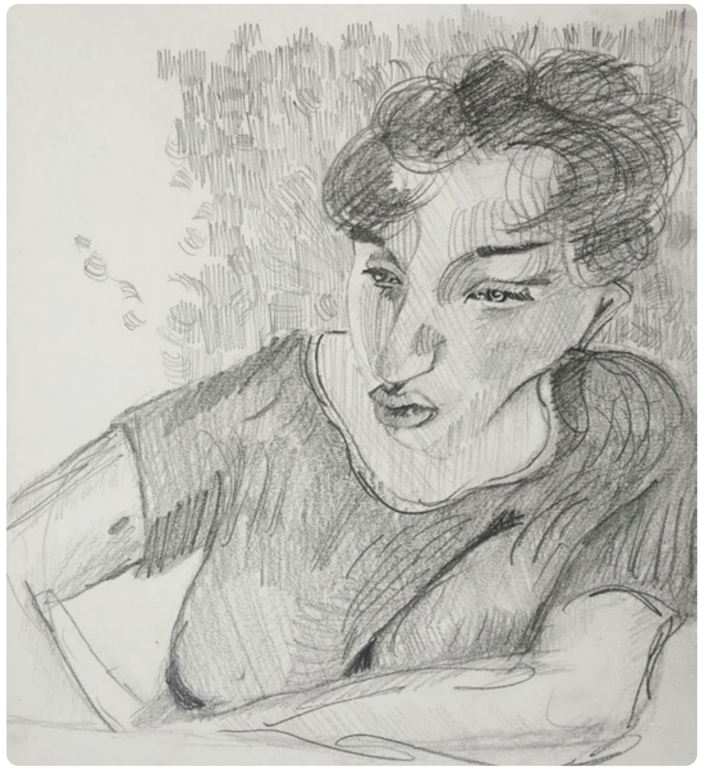


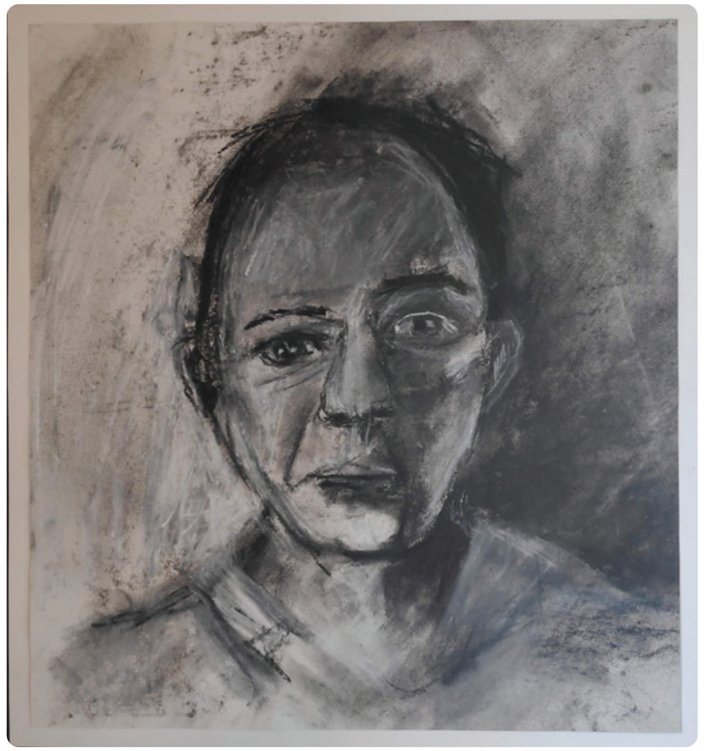
Free Falling

Cindy Létourneau-Fernandez

Felicidade Flor

Ane





Untitled

Hadiyah Ilyas

Untitled

Anna Donato

This is Who I Am

Mrudula Raju

LIFESTYLE

The Origin of Eczema and the Centuries-Old History Behind It

by Meghan Gallagher

Origin stories reveal the formative events — the victorious wins and momentary setbacks — that explain how a character got to where they are today.

And like any complex character, eczema's origin story follows a similar path: groundbreaking treatments built upon years of questions, trials and errors and revolutionary breakthroughs.

But what can eczema's origin story tell us about where we're headed today? Let's step back in time to discover the major milestones in eczema's history, understand how assumptions about eczema and its treatments evolved and, perhaps, catch a glimpse of the future.

Uncovering Eczema's Origin Story

Before eczema earned its formal title, descriptions of similar skin conditions appeared in ancient Egyptian texts.

"As far back as we can see, in one of the earliest known medical documents called the Ebers Papyrus thought to be written more than 3,000 years ago, there have been skin issues described," said Dr. Peter Lio, Assistant Professor of Clinical Dermatology and Pediatrics at Northwestern University's Feinberg School of Medicine.

While the document doesn't specify eczema, Dr. Lio noted it wouldn't be surprising if that were the case. Early remedies listed for "enduring itch" on the Ebers Papyrus included compresses of bean and onion mixtures as well as milk and sea salt.[1]

Hippocrates, traditionally thought responsible for the Hippocratic Oath and referred to as "the father of modern medicine," also contributed theories on the origins and treatment of eczema-like skin conditions around 400 BC.[2,3]

What's in a name? Eczema and atopic dermatitis

We can thank two English doctors, Robert Willan and Thomas Bateman, for coining the term "eczema" in 1817 to describe a fluid-filled, blistering rash (like a sunburn).[4] It's the first time we see the term appear, though it doesn't match the types of eczema we typically think of today.[5]

> In the early 1900s, as dermatology continued to distinguish itself from general medicine, doctors altered their approach to the study of the skin.

"Dermatologists began to differentiate between different types of skin conditions, including eczema, and to *categorize* them based on their symptoms and appearance," explained Dr. Lio. These new classifications helped doctors better understand and differentiate between similar-appearing conditions, like eczema and psoriasis, which allowed for more specialized studies.

A description of the most common type of eczema we know today appeared in 1933. Atopic came from the word "atopy," which describes a predisposition to respond immunologically to diverse antigens/allergens, and "dermatitis", which refers to inflamed skin.[6] From then on, atopic dermatitis defined what we most often think of as the most common form of eczema today: allergen-related, itchy and inflamed skin.

Revolutionizing eczema treatment with corticosteroids

In the 1950s, a revolutionary treatment for eczema arrived on the scene. "The development of corticosteroids, for the first time, offered significant and reliable relief for patients. Perhaps more importantly, it opened the door to learning about the condition and began the race to find non-steroidal treatments," said Dr. Lio.

Two researchers synthesized Compound F, which you may know more commonly now as hydrocortisone, in 1952.[1] Other corticosteroids, or topical anti-inflammatories, followed soon after.

Today, doctors prescribe varying concentrations of corticosteroids for eczema for their effectiveness in stopping the itch and inflammation. "Topical steroids are the mainstay of anti-inflammatory treatment," said Dr. Lio. "I wish they weren't. I'm a searcher and I want to find other things that are better and safer. But topical steroids are incredibly powerful, and when used correctly, they do a great job and are relatively safe."

You can pick up a mild corticosteroid over the counter, but a dermatologist must prescribe stronger concentrations. The stronger the corticosteroid, the more someone's risk increases for rare but painful side effects, like topical steroid withdrawal. Hence the continued push, as Dr. Lio noted, for more non-steroidal options.

Today's eczema research, your microbiome and the environment

Current eczema research focuses on the cause and effect between the bacteria, fungi and viruses on our bodies (our microbiome) and our intermittently itching skin. "We are now understanding that our environment and the microbiome are playing a crucial role in this condition," said Dr. Lio. "Something that has long been underappreciated."

Today we know more about our skin's barrier and its connection to our immune system. A recent study described people with eczema as having less microbial diversity (different kinds of bacteria) on the skin and in the gut.[7] Our microbiomes are "highly personal," and this discovery could reveal a path to more precise and personalized eczema treatments.[8]

New research also alerts us to the connection between polluted air, stress, diet and other environmental factors to eczema.[9] As the climate continues to change and urbanization rises, so does their impact on our immune systems and, as a result, our eczema.

What's next in eczema's story?

We must remember that dermatology, in contrast with other fields of medicine, is still quite young. There's much we know about eczema and much still to discover.

We've come a long way from the first iterations of milk and salt compresses, but our bodies are dynamic and ever changing. Determined doctors and researchers devote countless hours to eczema research and develop new treatments and theories every year.

"I wish more people knew that this has been with us for a long time and that it is a difficult problem that has no easy solution," noted Dr. Lio. "If it did, one of the great minds throughout history would have solved it already! It's not the patient's fault."

Even on days when it seems like the itching won't stop, it's important to remember you're not alone. Other people with eczema, doctors, researchers and caregivers — we're all part of the still unfolding story of eczema.

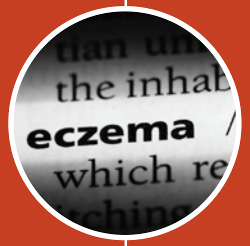
A Quick Timeline of Eczema's History

1550 BCE

The Ebers Papyrus text from ancient Egypt describes skin issues including remedies for "enduring itch."

400 BCE

Hippocrates contributes theories on the origins and treatment of eczema-like skin conditions.



1817

English doctors Robert Willan and Thomas Bateman coin the term "eczema" to describe a fluid-filled, blistering rash.

1933

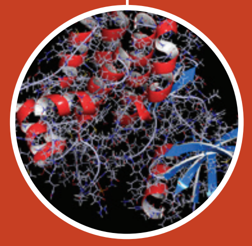
A description of atopic dermatitis, the most common type of eczema, appears.

1952

Two researchers synthesize Compound F, commonly known as hydrocortisone. Other topical corticosteroids follow soon after.

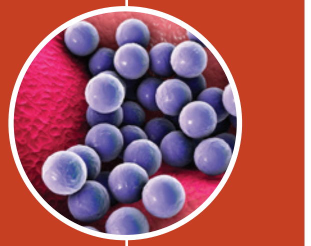
EARLY 21ST CENTURY

Expanding research ushers in new eczema treatments including biologics and JAK inhibitors.



TODAY

Current eczema research focuses on the cause and effect between our microbiome, our environment and our skin.



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LIFESTYLE

Scratch, Scratch, Swipe: Tips for bumbling your way through dating with eczema

By Meghan Gallagher

You're attempting to converse with your date, yet your mind keeps slipping back to the proverbial elephant in the room: When do I bring up my eczema? Or maybe you're creating your first dating profile and wondering where, or even if, to mention your presently flaring skin.

Eczema is not all that you are, yet it's no small part of who you are. Dating itself can feel like navigating a maze, even without the complexity of a chronic skin condition. You may feel more self-conscious or worried about how others perceive you — both across the table and online.

Remember, you're not alone, and these feelings are normal. Over 10% of people in the U.S. live with eczema, and, odds are, they're asking these same questions. We spoke with Lisa Sisemore, senior director of matchmaking at It's Just Lunch, as well as NEA Ambassadors from our community who shared their tips for navigating dating with eczema.

Assess (and reassess) your comfortability

You are under no obligation to talk about your eczema on your first, second or even third date. Take a moment to assess how you feel, whether swiping through profiles or getting ready for a night out.

"The earlier, the better," recommended NEA Ambassador Cynthea Corfah. "I'd rather get an understanding of how my potential partner feels about eczema early on to avoid any awkwardness during a flare-up. In my experience, most people are very understanding."

But if talking about eczema prevents you from enjoying your first date, the conversation can wait for another time. Only bring it up when you feel comfortable and prepared.

"The right time is whenever someone feels comfortable, typically around the third date," said Lisa. "Around the fourth or fifth date is usually when there's a true connection, but before the relationship really starts."

Bring up your eczema directly or indirectly — the choice is yours

When you are ready to share about your eczema, you get to decide how. You may want to take an early, direct approach like Cynthea or a more indirect route.

"As I get to know a potential partner better, eventually I will open up about my eczema," explained Jeremy Paredes, a fellow NEA Ambassador. Jeremy often prefers to invite questions about his eczema rather than bring it up in conversation. "For example, I'll wear a short sleeve shirt or shorts that expose my eczema, and they might ask about it."

You can also practice what to say ahead of time. A little preparation can go a long way to soothe your nerves (and may help prevent a flare).

Honesty, the best policy when talking about eczema

"With health, I have clients who come to me at all different stages. Some people are thoroughly aware of what's going on with their body; sometimes it's easier to discuss if you can see it," said Lisa.

"When I met my partner, my eczema was flaring all over my body," said Cynthea. "It helped that we had open and honest conversations about my eczema from the day we met. He was patient, eager to learn about my skin, compassionate and gentle. That gave me the space to bring my walls down and feel safe enough to be open to love."

Questions, as vulnerable as they feel, can help identify a curious and caring partner. Try to answer a date's questions honestly and not downplay your eczema's impact or how you feel.

Well-intended questions also provide valuable opportunities to educate your date about eczema and open communication helps lay the foundation of a strong relationship.

Prepare for a range of reactions (some may surprise you)

Everyone reacts to eczema, or any chronic condition for that matter, in different ways. Some people may be supportive and ask how your skin is doing. Others may become more apprehensive or begin to withdraw after you share about your eczema. Prepare yourself before the conversation for either reaction and anything in between.

Opening up about your eczema can be a risk. But it also carries an advantage. You can tell who sees you and understands you and who does not. Keep in mind there's nothing wrong with being choosy. You do not need to settle for someone who doesn't accept all of you.

> "When looking for a potential partner, I am quick to recognize whether my eczema pushes them away from me or if they don't mind at all. Those who judge people not by looks or a skin condition, but by you as a person as a whole, are those who I find myself gravitating towards and liking."
>
> ~ **Jeremy Paredes**, NEA Ambassador

"You're not alone in this journey," said Lisa. People might have had past partners who hurt them, or partners who told them or made them feel they are not capable of being loved for whatever reason, and that's just not true. Everyone has someone that they have enough in common with to share love and joy with."

The key to confidence? Practice.

In a society that values surface-level standards, eczema can affect your self-esteem and hold you back from the dating scene.

The key to moving forward? Learning to accept who you are and practicing confidence. Hold your head high and try dating anyway — even if you don't feel confident quite yet. The more you practice opening yourself up and engaging in vulnerable experiences, the more confident (and comfortable) you'll become over time. Dating with eczema is not always easy, but well worth taking the first step, whether that's creating a dating profile or asking someone out.

"Trust that there are people out there who will love you in all your skin's many forms," said Cynthea. "The right person will make you feel safe enough to be yourself, comfortable enough to share your struggles and will be an active partner in helping you manage your eczema. Don't settle for anything less. You are worthy of unconditional love."

Scan the QR code to hear more stories from Cynthea, Jeremy and other NEA ambassadors about what it's like dating with eczema.

Lisa Sisemore is the senior director of matchmaking at It's Just Lunch, a matchmaking service for busy professionals with 110 locations nationwide. With 31 years of experience, Lisa was named Matchmaker of the Year in 2020 and 2021.

COMMUNITY POV

How I Own My Eczema with 4 Reminders

by Ashley Ann Lora

During your healing journey, you may have heard phrases like “accept your eczema” and “own the skin that you’re in.” But what does that really mean, and what does that look like for you?

After Eczema Expo ‘22, I partnered up with NEA to hold monthly support groups so that those who attended could stay connected and keep the “high vibes” going. Recently, in one of our sessions, I shared with members “R3S” — Responsibility, Research, Resource Bag (hence “R3”) and Support (hence “S”). Now, I know R3S doesn’t sound like a “sexy” acronym (because let’s be honest, it isn’t), but it gets the job done. If I can sum up what “owning my eczema” means to me, it’s R3S.

With almost 30 years of living with atopic dermatitis under my belt, I have had quite the journey of figuring out what works and what doesn’t work for me. When I began owning my eczema and fully standing responsible for my health, my life changed for the better and so did my healing journey with eczema.

So, how did I begin owning my eczema? It starts with R3S — let’s break it down!

1. Responsibility

Owning my eczema means that I am standing 100% responsible for my condition. This means that I am in charge of my body and how I take care of it.

Growing up, I blamed everyone and everything else for why I was flaring up. Not once did I stand responsible for my health and consider that I could make my life easier and my eczema more manageable by understanding my triggers, watching what I was eating, moisturizing appropriately and so much more.

Now, it’s important to note that standing responsible does not mean that I am at fault for why eczema is occurring in my life. In this context, I will add that the road to healing is in taking responsibility. We may come across individuals like our parents or healthcare professionals who support us, but ultimately, it is our responsibility to manage our lives the best way we can now that we’re living with eczema.

2. Research (and know your options)

Owning my eczema means that I do my research and I know the options available to me.

In 2014, I remember Googling “eczema” for the first time and coming across all of these resources and tools that I had never heard of before. The research I was finding shattered all of the limiting beliefs I had about eczema — that there’s no way to control it and no one knows what I’m going through. It taught me that there were daily actions I could take to better manage my skin, like avoiding triggers, eating better and co-creating a treatment plan with my doctor.

When I did my research and learned about the different ways I could better manage my eczema, I felt confident and powerful in myself. You, too, can feel confident in your healing journey when you do your research and you know your options.

3. Resource Bag

Owning my eczema means that I am equipped with the proper tools and resources to handle any flare-up that comes my way.

I love sharing this concept that I created for myself called the “resource bag.” It’s a mental toolkit and a step-by-step process to help me manage my eczema whenever I am flaring up.

Some of the items in my resource bag include breathing, putting my hands under cold water, moisturizing and using ice packs when needed. (Due to the severity of my skin right now, I have been accessing my resource bag at least four times a week). When I use my resource bag and take these steps, I feel an immediate relief.

Having a resource bag helps me stay in control and build the confidence I need to better manage my eczema. I invite you to build your own resource bag. What would you include in it? What has worked for you in the past? Note that you can always add and remove items from your bag depending on what is supporting you at the moment.

4. Support

Owning my eczema means that I know I’m not alone on this journey and that I am supported by my community.

It took nearly 22 years for me to learn that there were over 31 million Americans living with eczema. That’s a long time to believe that I was the only one in the world with this condition.

When I began to seek support from my community, my confidence in managing my eczema grew, and so did my resource bag! Why? Because I began learning about the experiences of others, including what worked and what didn’t work for them. I was also able to see how others thrived in their lives while living with eczema and that made me think, “If they can do it, so can I.”

> Know that you’re not alone and that there is an entire community ready to support you. Now I say, “If I could do it, so can you.”

Owning your eczema doesn’t have to be hard. You can take daily action steps to build your confidence and learn about the various ways to lessen your flares. Start by standing responsible for your health, doing your research, creating a resource bag and seeking support. I’m right here with you!

The NEA Questionnaire

Inspired by The Proust Questionnaire, and popularized by Vanity Fair, we're introducing our very own NEA Questionnaire. French author Marcel Proust believed that by answering a series of curated questions, an individual reveals their "true nature." The NEA Questionnaire series aims to highlight prominent figures in the eczema community in an effort to better understand the people behind the impact they've had on the community and the passions that drive them.

We're kicking off this series with our very own Julie Block, NEA President and CEO. Get to know Julie:

What is your idea of perfect happiness? Catching an ocean wave, hearing children's laughter, groovin' at an outdoor concert and HUGS! **What is your current obsession?** Ted Lasso the TV series, Musician Rozzi Crane, Hearts game on my phone. **Which living person do you most admire?** My brother, Bruce. He's my hero. **Where do you go to find peace?** Any body of water; the ocean, rivers, creeks, lakes, etc. And often my backyard hammock with a good book. **What is your greatest fear?** Being held in captivity in a foreign country. **What is the quality you most like in yourself?** I'm accepting, appreciate many points of view, trusting and calm (most of the time!). **Which words or phrases do you most overuse?** "Ugh!" and "curious." **When and where were you happiest?** Floating in the Mediterranean Sea on a recent vacation — a close second to the births of my two sons many years ago now. **Which talent would you most like to have?** Any musical talent at all! Spoons, singing, trumpet, bongos, anything! **If you could change one thing about yourself, what would it be?** I wish I enjoyed cooking and was good at it. **What do you consider your greatest achievement?** Professionally, without a doubt, serving the NEA community and continually learning how to be the best leader I can be. Personally, two kind, caring, smart and dare I say handsome sons — who continue to love up on their mama. **If you were to die and come back as a person or a thing, what would it be?** My dog Ollie, best life ever! **Where would you most like to live?** Exactly where I am. **What is your most treasured possession?** My home — it's where the heart is, after all. **What do you regard as the lowest depth of misery?** Not exactly sure, but the loss of a child must rank at the top. I can't honestly say I've experienced the depth of misery. **What is your most marked characteristic?** Warmth. **What do you most value in your friends?** My true friends care for me and love me just as I am. And all the GIGGLES we share! **Who is your hero of fiction?** Winnie-the-Pooh. **What is the best piece of advice you've ever been given?** Be you — you are enough. **Which historical figure do you most identify with?** Not sure I identify with her exactly, but Ruth Bader Ginsburg is a hero. **What is it that you most dislike?** Hatred. **What is your greatest regret?** Not trusting my instincts when I should have. **What is your motto?** Do you. **What do you wish more people knew about eczema?** I wish people knew how all-encompassing eczema can be — the confusion, helplessness, all the effort it takes to manage and get help, the physical and psychosocial pain, etc. etc. etc., and the impact on loved ones. I wish everyone knew there is a deep well of understanding, support and hope no matter how you experience the condition. I wish people knew you can turn your pain and struggles into connection, learning and action with NEA. :)

May is Itching for a Cure Month

ITCHING FOR A CURE

Eczema champion ecz-traordinaire, Dr. Peter Lio, is challenging you to raise funds for eczema research — and he is matching the first $30,000 raised in May!

Join Itching for a Cure by registering, setting your fundraising goal and picking your favorite fundraiser — a walk, a party, a bowling night, an online fundraising drive ... the possibilities are endless!

Together, we can create a world without eczema.

Register today to raise funds to help end eczema

Ecz-pert Tips for Bathing with Eczema

By Natalie Staples

What do you do nearly every day that can affect your eczema? Bathing! It's important to care for your skin in and out of the bath or shower. From oatmeal baths to bleach baths, there are several different ways to care for your skin whether you're in the middle of a flare or aiming to avoid one in the future.

Why is bathing important for eczema management?

Baths are an effective way to care for your skin and your skin barrier. A skin barrier that is inflamed or dry is vulnerable to bacteria and allergens. A regular bathing and skin care routine can strengthen your skin barrier and help you retain moisture. Additionally, wet skin can better absorb medication and increase its effectiveness. There are several different remedies you can apply on a daily basis in your bath routine.

How to bathe during an eczema flare (or to help avoid one)

Dr. Jeff Yu, a board-certified dermatologist and assistant professor of dermatology at Massachusetts General Hospital, noted that you should "not use HOT water. Lukewarm water is best for bathing because the hotter the water, the dryer the skin will be." As you bathe, be sure to not vigorously scrub with a loofah and use a mild cleanser. Dr. Yu advised, "Avoid fragrances in the bath. Fragrances are by far the most common irritants and allergens present in bathing products. Even though something may be labeled "for babies," it can still elicit an eczema flare."

During an eczema flare, there are a few other types of products you may try. For example, you may choose to bathe in more than just lukewarm water. Bathing with mild bath oils without fragrances or with baking soda by adding a quarter of a cup to the bath are two good methods. If you feel that your skin is stinging in a bath, adding a cup of salt may provide some relief. Moreover, you may also wish to try adding colloidal oatmeal or apple cider vinegar to your bath.

Soak and seal is an excellent method for preventing flares and re-moisturizing your skin. During the bath, be sure to soak in lukewarm water for five to 10 minutes. Bleach baths can be extremely effective. You can add one-fourth to a half-cup of household bleach to the bath. Be sure not to submerge your head or rub your eyes. If caring for a child, supervise them. After bathing, rinse your skin with water. Bleach baths help to balance the pH of your skin and have anti-inflammatory properties. If you're unsure of this method or others, consult your dermatologist.

What should you do after a bath?

Don't forgo the moisturizer! The "seal" part of the soak and seal method is vital.

> "Moisturizing immediately afterwards is often overlooked. Moisturize within 2–4 minutes if possible. The skin dries the fastest after taking a bath and lathering on that thick moisturizer immediately afterwards will prevent drying of the skin."
>
> **~ Dr. Yu**

There are few different types of moisturizers to consider. NEA's Seal of Acceptance™ is given to moisturizers free of fragrance, dyes and other common allergens. Additionally, thick ointments or creams allow for the best hydration. Alternative remedies, like sunflower oil, may also improve your skin barrier and may be applied directly after a bath to help the skin retain moisture — so be sure to apply it in a timely manner.

How often should you bathe if you have eczema?

Dr. Yu said that caregivers of children with eczema often ask this question. He shared that "There is really no evidence to suggest that bathing daily versus less frequently helps or hurts eczema. However, the most important thing to remember is to moisturize immediately afterwards. I also tell parents that if the child is visibly dirty or has environmental allergies and has come in contact with possible allergens, it's best to wash off those potential triggers for an eczema flare." If you'd like more guidance about how often to bathe with eczema, consult your doctor.

In sum, bathing is an important way to care for your skin barrier that can be a part of your regular routine. Get back to the basics by implementing a bath regimen, and don't forget to moisturize!

Some things to remember when bathing:

- Take at least one bath or shower a day
- Bathe or shower in lukewarm (not hot) water for 5 to 10 minutes
- Avoid scrubbing your skin with a washcloth or loofah
- Use a gentle cleanser (not soap)
- During severe flares, limit the use of cleansers to further avoid irritation

Some things to remember when moisturizing:

- Use a high-oil content moisturizer twice a day to improve hydration and protect the skin barrier
- Moisturize hands every time you wash them or they come into contact with water
- Schedule your bathing and moisturizing routine at night, just before bed. This can help your skin better retain its moisture
- If you have eczema on your hands, soak your hands in water, then follow with an application of your prescription medication (if you use one) and moisturizer. Wear cotton gloves over your hands while you sleep to help "lock in" the moisturizer

Breaking Down the Essential Elements of Shared Decision Making

The NEA research team has published its latest paper on shared decision making (SDM), or the process through which patients and/or caregivers and healthcare providers (HCPs) work together to make informed decisions about treatments and/or care plans.

The survey provided a number of factors related to SDM, asking respondents (840) to rate each on a scale from 0 (not important at all) to 4 (absolutely essential), as well as how often these factors were true with their current eczema HCP. Factors included aspects about the HCP, the patient, the visit and the guidance provided. Respondents were considered to have their "needs met" if they indicated a factor was very important or absolutely essential and also reported it as usually or always true.

80% of respondents

reported their **needs were met** for the factors they deemed most essential for facilitating SDM

The percentage of respondents who indicated their needs were not met ranged from 11.4%–36.3%.

Aspects about the HCP

Although the current study showed that few eczema patients perceived that the race, ethnicity and gender of their HCP matching their own was important for SDM, **as many as half of all Black respondents did identify this as a key factor for race and ethnicity.**

Aspects about the patient

~92% of respondents

said that their **own health literacy**, the ability to **articulate their experience** and **feeling comfortable enough** to do so were very important or absolutely essential for facilitating SDM.

~88% of respondents felt that these factors were usually or always true for them with their current eczema HCP.

Aspects about the visit and guidance

Over **85% of patients reported it was important to not feel rushed** during their appointment. Around one-third said this was an unmet need with their current HCP.

42.4% of patients did not find in-person visits to be important for SDM, which may suggest the possibility for more patients and HCPs to utilize virtual visits when applicable.

Of the eczema patients and caregivers who reported that having an **HCP initiate the discussion about treatment options is important/essential to them**, 39% reported unmet need with their current HCP.

Overall, this paper revealed that eczema patients and caregivers want to be involved in decision making for their treatments and that SDM is more likely to be facilitated when patient education and empowerment are combined with HCPs who initiate treatment discussions and are compassionate listeners to patient perspectives.

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

Foster, E, Loiselle, AR, Thibau, IJ, Smith-Begolka, W. Factors facilitating shared decision making in eczema: Met and unmet needs from the patient perspective. *JAADi.* 2023.

The most trusted mark in eczema products just got better.

NEA first created the Seal of Acceptance™ in 2008 to make it easier for people with eczema or sensitive skin to find suitable personal care products. In the years since, the Seal has continued to evolve as new science emerges about eczema, ingredients and formulations.

For a product to obtain the Seal, it must meet the strict standards established by our Scientific Oversight Committee – a panel of leading dermatologists, allergists and eczema experts – and undergo testing for sensitivity, irritation and toxicity, as well as a review of ingredients and formulation data.

In 2023, the Committee updated the Seal criteria and created the Ecz-clusion List of ingredients that won't be allowed in any amount. As always, when you see the Seal, you can be sure the product meets the highest standards and has undergone rigorous testing and scientific review.

Our goal is not only to help you find eczema-friendly products, it's also to drive manufacturers to do better, creating products that are free of known allergens and irritants. You can find personal care and household products with the Seal in the Eczema Product Directory – and check back regularly for new additions. Keep in mind that eczema is different for everyone and a product that works for one may not work for another, or even for the same person over time.

Scan the QR code to learn more and visit the directory

EczemaExpo**23**

REGISTER NOW FOR ECZEMA EXPO 2023

We're gathering our entire eczema family together!
Join us in Orlando, FL June 22–25.

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