



National
Eczema
Association

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NEA Magazine

Research, Support and Education for Those Affected by Eczema





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



NEA Magazine

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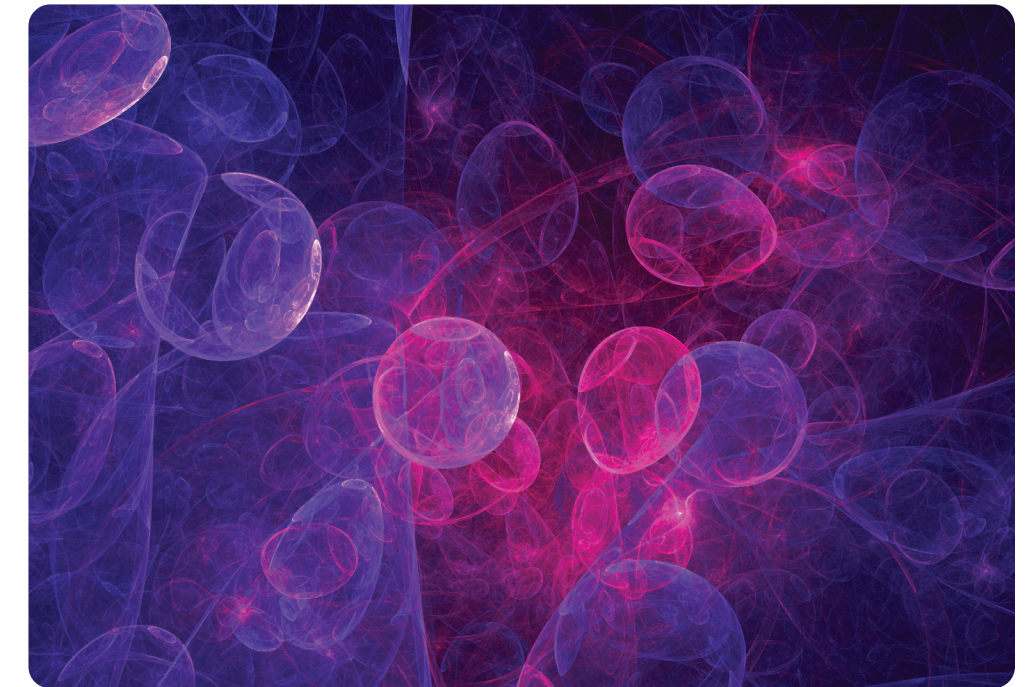
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Biologics and a New Wave of Treatments

Biologics are continuing to change the future of eczema treatment. But what are biologics, exactly? How do they work and who are they for? Here's everything you need to know from top eczema experts.

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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Letter from Julie

Greetings and happy spring! I write to you today with great anticipation for the renewal that comes with the season, and the promise ahead for our eczema community.

Fueling our anticipation and excitement is the wave of new eczema treatments nearing the finish line of FDA approval. You, eczema patients and caregivers, have been part of many NEA initiatives, including our PFFD meeting in 2019, NEA Ambassador meetings with drug manufacturers as well as participation in NEA surveys, that ensure patients are at the heart of therapeutic development. In our last issue we set the stage by exploring the development of Janus kinase inhibitor (JAK) therapies and how they work to relieve eczema symptoms, and in this issue, on page 8, we explore the science of biologics and their expanding role in treating eczema.

With so much eczema treatment news expected to break in coming months, we've created a New Treatment information hub on our website where you can check all the latest updates in real time at NationalEczema.org/NewTreatments. As soon as we know, you'll know, too.

Spring has also given us good news in the fight against Covid-19. Many of you reached out with important questions about eczema and vaccines. In our Ask the Ecz-perts article on page 19 we answer your inquiries and provide valuable information about the Covid-19 vaccines and eczema, so you can make the most informed decision, often in consultation with your healthcare provider.

Guiding all of our programs and initiatives at NEA is our new strategic plan, Blueprint 2025, launched in late January. Looking ahead, we have established a clear, powerful path that will guide us together over the next five years and beyond. Our vision is a world without eczema. Our mission is to be the driving force for an eczema community fueled by knowledge, strengthened through collective action and propelled by the promise for a better future. Thank you for joining and supporting our efforts to bring our aspirations to reality.

Mark your calendar for Eczema Expo 2021, taking place August 27-29. This Expo will be held virtually again, allowing the global eczema community to gather to learn, get support and connect.

Be safe, be well and stay tuned.

Yours with gratitude and wishes for good health,

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

New Board Members, Podcasts, Eczema Expo, Blueprint 2025, Ambassador News and a New NEA Baby!

Welcome to NEA's Newest Board Members

NEA is proud to welcome three new members to our Board of Directors. Amy Chnelich, Lynell Doyle and Justine Scott officially joined the NEA board in February. Amy Chnelich is a pediatric intensive care nurse with over two decades of experience in the healthcare sector. Her daughter has lived with eczema her entire life. Lynell Doyle comes to NEA as an eczema warrior and a caregiver. She lives with eczema, as do her two sons. Lynell describes herself as a "dedicated and passionate person who has a vested interest in the success of NEA's continued growth and availability to people with eczema." Justine Scott first came to NEA in the role of a caregiver: her daughter lives with eczema. Justine, in her own words, joined NEA's board to "contribute to an organization that has given so much and that truly makes an impact in the lives of those with AD." From the entire NEA community, welcome Amy, Lynell and Justine!

Eczema Out Loud – Tune In to NEA's New Podcast

In February, NEA launched a new podcast series – Eczema Out Loud – hosted by NEA team member, Dani Morshead, with the goal of educating and entertaining listeners with stories and interviews from the eczema community. The podcast launched with the debut episode "Itchy in Love," about relationships and eczema, followed by "The Atopic March" in March, featuring an in-depth interview

with Dr. Ari Zelig about the interplay of eczema, asthma and allergic rhinitis. Eczema Out Loud is free and available for download on any of the following platforms: Spotify, Apple Podcasts, Anchor, Breaker, Castbox, Google Podcasts, Overcast, Pocket Casts and RadioPublic. Stay tuned for episodes on new treatments and clinical trials in the months ahead.

Eczema Expo 2021 – Mark Your Calendars for August 27-29

For Expo 2020, we had to transition quickly (and with heavy hearts) to a virtual format, but in the end it exceeded our wildest expectations (and we were able to engage more community members from around the world).

In 2021, we've got this thing dialed in and can't wait to share more details about all that's in store for you. We're thrilled to be able to welcome everyone virtually from all over the world. Mark your calendar and keep an eye out for updates.

NEA's New Strategic Plan: Blueprint 2025

In January, NEA announced a new strategic plan, Blueprint 2025, that will guide the organization's programs and initiatives for the next five years and beyond. At the heart of this plan is a connected, empowered community united to fulfill the promise of a better future. With you, our community, we will energetically pursue the vision of "a world without eczema." With you, we commit to create community, generate knowledge and take collective action to improve the lives of people affected by eczema.

The full NEA Blueprint 2025 is available at NationalEczema.org/About-NEA/Strategic-Plan-2025.

Itching for a Cure

Itching for a Cure (IFAC) is NEA's annual campaign to raise funds for eczema research and build eczema awareness. This year, IFAC is taking place from May 1 - 15. NEA is the largest private funder of eczema research in the country. We depend on donation support from our community to invest in research that improves care for all of us. Our goal is to raise \$20,000 this year so we will need all hands on deck! You can help shape the field of eczema research and change the future for millions of people! Sign up to fundraise for Itching for a Cure at ItchingForACure.org.

NEA Ambassadors – Advocating for the Eczema Community

NEA Ambassadors offers meaningful opportunities to learn and participate in volunteer opportunities in service to the greater eczema community.

Legislative season is in full swing and NEA Advocacy Ambassadors are busy advancing NEA's policy priorities, which are:

- To raise awareness of how eczema affects the lives of those with the disease and their families
- To ensure access to affordable, effective eczema treatments – this includes tackling insurance issues that you may encounter at your doctor appointments or at the pharmacy counter

In 2021, the Advocacy Ambassadors' specific goals include:

- Establishing/strengthening relationships with legislators
- Playing a critical role in advancing legislation at the local, state and federal level
- Helping to grow NEA Ambassadors by encouraging others in the community to join

“Taking part in advocacy drives home the importance of raising our voices and sharing our stories, so that we’re heard, and taking part in advocacy events so that we are seen. It was incredibly inspiring to see our State Senator and State Representative supporting and fighting for us. Knowing they see and hear us really helps to chip away at that feeling of being invisible.”

~ Ambassador Amy

Amy participated in a recent press conference about healthcare access with Pennsylvania legislators. Learn more about NEA's policy priorities at NationalEczema.org/advocacy and join NEA Ambassadors at NationalEczema.org/ambassadors.



GALDERMA

We are committed to driving innovation in dermatology and bringing solutions to patients living with Eczema

NEA Welcomes a New Baby to Our Team!

In February, NEA's Director of Development Rachel Lee Holstein welcomed a baby girl into the world. Baby Amara was born February 17 and the NEA team just can't get enough of her photos. Congratulations Rachel Lee and welcome Amara – we can't wait to meet you.



ECZEMA: UNDER CONTROL. SO ROLL UP THOSE SLEEVES.

DUPIXENT is a breakthrough in the treatment of uncontrolled moderate-to-severe eczema (atopic dermatitis).


Approved for ages 6 years and up.

SHAWN, REAL PATIENT.
Individual results may vary.

DUPIXENT helps heal the look and feel of skin. And it's not a cream or steroid. It's a biologic that continuously treats eczema over time—even between flare-ups. See and feel a significant difference with:

Clearer skin • Fast itch relief

- In clinical trials at 16 weeks, 37% of adults and 24% of teens (ages 12-17) saw clear or almost clear skin vs 9% and 2% not on DUPIXENT.
- And 38% of adults and 37% of teens (ages 12-17) had significantly less itch vs 11% and 5% not on DUPIXENT.

DUPIXENT® 
(dupilumab) Injection
200mg • 300mg

— TALK TO YOUR ECZEMA SPECIALIST AND VISIT DUPIXENT.COM OR CALL 1-844-DUPIXENT (1-844-387-4936) —

INDICATION

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

IMPORTANT SAFETY INFORMATION

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

Before using DUPIXENT, tell your healthcare provider about all your medical conditions, including if you: have eye problems; have a parasitic (helminth) infection; are scheduled to receive any vaccinations. You should not receive a "live vaccine" if you are treated with DUPIXENT; are pregnant or plan to become pregnant. It is not known whether DUPIXENT will harm your unborn baby. There is a pregnancy exposure registry for women who take DUPIXENT during

pregnancy to collect information about the health of you and your baby. Your healthcare provider can enroll you or you may enroll yourself. To get more information about the registry call 1-877-311-8972 or go to <https://mothertobaby.org/ongoing-study/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 (hypersensitivity), including a severe reaction known as anaphylaxis. Stop using DUPIXENT and tell your healthcare provider or get emergency help right away if you get any of the following symptoms: breathing problems, fever, general ill feeling, swollen lymph nodes, swelling of the face, mouth and tongue, hives, itching, fainting, dizziness, feeling lightheaded (low blood pressure), joint pain, or skin rash.

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

The most common side effects in patients with atopic dermatitis include injection site reactions, eye and eyelid inflammation, including redness, swelling, and itching, and cold sores in your mouth or on your lips.

Tell your healthcare provider if you have any side effect that bothers you or that does not go away. These are not all the possible side effects of DUPIXENT. Call your doctor for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to

the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Use DUPIXENT exactly as prescribed. Your healthcare provider will tell you how much DUPIXENT to inject and how often to inject it. DUPIXENT is an injection given under the skin (subcutaneous injection). If your healthcare provider decides that you or a caregiver can give DUPIXENT injections, you or your caregiver should receive training on the right way to prepare and inject DUPIXENT. **Do not** try to inject DUPIXENT until you have been shown the right way by your healthcare provider. In children 12 years of age and older, it is recommended that DUPIXENT be administered by or under supervision of an adult. In children younger than 12 years of age, DUPIXENT should be given by a caregiver.

Please see Brief Summary on next page.

SANOFI GENZYME  REGENERON

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YOU MAY BE ELIGIBLE FOR COPAY ASSISTANCE* *Limitations apply. Visit DUPIXENT.com for full program terms.

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

What is DUPIXENT?

- DUPIXENT is a prescription medicine used:
 - to treat people aged 6 years and older with moderate-to-severe atopic dermatitis (eczema) that is not well controlled with prescription therapies used on the skin (topical), or who cannot use topical therapies. DUPIXENT can be used with or without topical corticosteroids.
- DUPIXENT works by blocking two proteins that contribute to a type of inflammation that plays a major role in atopic dermatitis.
- It is not known if DUPIXENT is safe and effective in children with atopic dermatitis under 6 years of age.

Who should not use DUPIXENT?

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

What should I tell my healthcare provider before using DUPIXENT?

Before using DUPIXENT, tell your healthcare provider about all your medical conditions, including if you:

- have eye problems
- have a parasitic (helminth) infection
- are scheduled to receive any vaccinations. You should not receive a “live vaccine” if you are treated with DUPIXENT.
- are pregnant or plan to become pregnant. It is not known whether DUPIXENT will harm your unborn baby.
 - **Pregnancy Exposure Registry.** There is a pregnancy exposure registry for women who take DUPIXENT during pregnancy. The purpose of this registry is to collect information about the health of you and your baby. Your healthcare provider can enroll you in this registry. You may also enroll yourself or get more information about the registry by calling 1 877 311-8972 or going to <https://mothertobaby.org/ongoing-study/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.
- DUPIXENT is given as an injection under the skin (subcutaneous injection).
- If your healthcare provider decides that you or a caregiver can give the injections of DUPIXENT, you or your caregiver should receive training on the right way to prepare and inject DUPIXENT. **Do not** try to inject DUPIXENT until you have been shown the right way by your healthcare provider. In children 12 years of age and older, it is recommended that DUPIXENT be administered by or under supervision of an adult. In children younger than 12 years of age, DUPIXENT should be given by a caregiver.

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

What are the possible side effects of DUPIXENT?

DUPIXENT can cause serious side effects, including:

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

The most common side effects of DUPIXENT in patients with atopic

dermatitis include: injection site reactions, eye and eyelid inflammation, including redness, swelling and itching, and cold sores in your mouth or on your lips. 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
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Issue Date: June 2020

DUP.20.06.0310

Eating junk food when super stressed cause dang it I just -need- it sometimes 🤪

@kathdanae

Kissing my cat’s little head

@aly_.mer

alcohol. cheese. chocolate. musaka. tomatoes. 🥺🥺🥺🥺

@sanguinaki

Eye make up 🧴👁️👁️

@hellendockx

Pizza, cheese, cake, bread, milkshake, pasta, ice cream, Girl Scout cookies

@clarebeareats

NEA PLAYLIST

What song are you playing on repeat? Here’s our NEA community-sourced spring 2021 favorite songs. Enjoy!

Encore and Last Piece by GOT7 pls ❤️

@j_aanny

Purple Hat by Sofi Tukker

@christinecutaran

Sunbathe by Miguel & Tainy

@kalisem_

Crashing (featuring Bahari) by Illenium

@christinecutaran

Picnicking on grass on a sunny day

🥰🥰🥰🥰

@littlestbritt

Big ol’ Hot bath with essential oils and epsom salt, wearing athleisure, hot cheetos, and perfume. Give me that flare up and dry skin!

@whenravenchats

Family bike ride in the Keys - I was so sweaty, red, and flared but I got quality family time. Doesn’t happen often with teenagers in the house! ❤️

@eczemaroad

Omg the pain i go through being an equestrian, I’m completely allergic to my own horse and on a scale of 1 to 6 of how allergic you can be to horses I’m a 5 🥺🥺. I get covered in rashes but its worth it lol

🥰❤️❤️

@cheyenne.phyn

Dynamite by BTS

@ayeshailyas21

Lowdown by Boz Scaggs

@amberjewett

My love will never die by Claire Wyndham

@amtire14

People Like Us by Kell Clarkson

@vissbec

Hot Blooded by Foreigner

@adelina_cantu

More by Electric Guest

@cresentvamp

Bluebird by Alexis French

@kerr.lewis

Love story (Taylor’s version)

@patriesque

It’s All Right

by Huey Lewis & the News

@nitewing3439

HEARD ON THE STREET

We asked. You answered.

You know it’s going to cause a flare but you do it anyway. What triggers are worth it?

100% worth it holding my dogs and my cat. I’ll just take a benadryl after, I gotta let them know I love them.

@junosmall

Hot showers & perfume 🥰

@tootah_ahmad

existing lol

@vronfbaby

Human by Christina Perri

@amandagolden789

Midnight Sky by Miley Cyrus

@oneeagleone

Memories by David Guetta & Kid Cudi

@caitlin_boesenhofer

Dream Girl by Ir-sais

@thebeautycafeWITHdr.nyorita

Perfect Now

by Louis Tomlinson

@emiliadapotato

Lucky Daye by Real Games

@iharrydo

Zen switch (produced by me when I got past a challenging eczema flare up) antiedote

@thereefle

Trouble by Welshley Arms

@maddy_loves_art

Cola by Lana Del Rey

@emilyfender13

RESEARCH

BIOLOGICS ARE CHANGING THE LANDSCAPE OF ECZEMA TREATMENT

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

The pipeline of promising treatments for atopic dermatitis (AD) is undergoing unprecedented expansion, and includes topical, oral and injectable therapies. In January 2021, the first article in this series reviewed what is coming for a new class of oral and topical drugs, the Janus kinase inhibitors (JAKs). In this second article, we take a look at new biologics on the horizon. Interest and growth in this area of drug development has been fueled by research highlighting the contributions of the immune system in disease onset and progression, as well as results from clinical trial and real-world use of dupilumab (i.e. Dupixent), the first biologic FDA-approved for moderate-severe AD.

IMMUNOLOGY OF ECZEMA

Atopic dermatitis (AD) is caused by both an “elevated” immune response within the skin and a defective skin barrier which can have underlying genetic or environmental factors (like allergens). The bacteria that call the skin home (such as *Staphylococcus aureus*) can also play a role in AD.¹

Years of dedicated scientific studies have teased out important clues about specific immune responses that contribute to AD and its symptoms. Cells of the immune system, called **T cells**, secrete messengers called **cytokines** and **interleukins (IL)** that tell other immune cells to get involved, leading to inflammation, signal structural cells of the skin (keratinocytes) to break down the skin barrier and even cause itch (**Figure 1**). The biologic dupilumab works to inhibit the activity of two key ILs in AD, IL-4 and IL-13. Now, several additional cytokines and ILs are also thought to play a role in AD — meaning more potential options for future biologic therapies.

BIOLOGICS: WHAT ARE THEY AND HOW CAN THEY IMPROVE TREATMENT OF ECZEMA?

A biologic is a drug made from biological (living) sources like cells from humans, animals, plants, fungi or microbes. Biologic drugs are sometimes called “biologic response modifiers” because they change a process already occurring in cells or for a particular disease. In AD, new biologic drugs can modify the elevated immune response driving the disease.

Some people with AD can be treated with medications applied to the surface of the skin (topical medications) to ‘turn down’ inflammatory immune responses and control itch. Others have more severe disease that is resistant to topical treatments and needs systemic (i.e. ‘whole-body’) types of medications to better control their AD and improve quality of life.

Traditional ‘whole-body’ systemic medications for AD include broadly immunosuppressive agents such as cyclosporine and methotrexate. Dupilumab is also considered a systemic agent, in that it acts on the whole body, but due to its ability to target only a specific component of the immune response (the IL-4 **receptor** alpha), it is not immunosuppressive and has offered a much-needed new approach for the treatment of moderate-severe AD. Biologics for a number of immune-mediated diseases have offered a revolutionary way to more directly target key immune response pathways involved in disease, while leaving other immune responses unaffected. Biologics for diseases like psoriasis and asthma have been available since 2003 and provided clues about how a similar approach for AD could be possible.

A biologic, such as dupilumab, is made in a laboratory by cells that produce human **monoclonal antibodies** (mAb), a protein made up of amino acids. These mAb work similar to antibodies made by the body during an immune response to a virus or a bacteria, but instead of targeting the microbe, they can target specific immune cells or proteins in the body, bind to them tightly and prevent them from exerting their effects or even get rid of them. Currently, biologic mAb need to be injected in order to be effective, since taking them through the digestive system would disrupt their three-dimensional protein structure and render them unable to bind to their targets — much like a key needs to be a certain configuration to open a lock.

“Some biologics in early development can actually kill some of the inflammatory cells rather than making them quiet,” according to Dr. Eric Simpson of Oregon Health and Science University, and chair of NEA’s Research Advisory Committee, one of the clinical researchers working to take biologics for AD through clinical trials. “This could lead to prolonged remission times even after the drug is stopped, which is very exciting!”

A BIOLOGICS REVOLUTION FOR AD TREATMENT IS ON THE WAY

Dr. Emma Guttman-Yassky, chair of Dermatology and Immunology at the Icahn School of Medicine at Mount Sinai in New York said, “This is a very exciting time for biologics in AD. Research into the immune mediators of AD opened doors to tremendous scientific development. It is a busy field of study. With AD there is a need to target different immune activities to achieve 100% clearance in all patients. Further, some of these biologics can also work for asthma.”

Not only can AD differ from patient to patient depending upon age, race, whether the patient has a genetic mutation in filaggrin (causing skin barrier disruption) and other factors, response to treatments can also be variable² — which is in part why treatment of AD is not a ‘one size fits all’. The goal of having a myriad of options to treat moderate-severe AD, and eventually approach treating each patient’s disease in a more personalized way, is currently driving development of over 25 different biologic drugs with more than 10 unique IL and cytokine targets. Figure 1 shows many of these current drugs in development and which immune pathways they are intended to inhibit. Typically, only one out of several thousand drugs makes it through clinical trials, FDA approval and into use³ due to limited efficacy, side effects, inability to scale up production or drug instability among other reasons. Indeed, biologics targeting IL-17C and IL-33 have been tried and failed in AD clinical studies, according to Dr. Simpson. However, several new biologics are showing promise in clinical trials, such as tralokinumab, lebrikizumab and nemolizumab, which are furthest along in development. Dr. Guttman-Yassky said, “Patients who do not respond to other drugs can use biologics as the first or second line of treatment.”

Tralokinumab

Tralokinumab (LEO Pharma) acts by targeting IL-13, which is one of the cytokines that tells other cells of the immune system to get involved in the inflammatory response. Two long-term Phase III studies (52 weeks) of safety and efficacy of tralokinumab for treating

moderate-severe AD were published in 2020 with hundreds of adults (18 and older) in each study.⁴ Trials for treatment of adolescents and more long-term trials are currently being recruited.⁵ In the published studies, patients were treated with 300 mg of tralokinumab injected subcutaneously every two weeks. Researchers noted improvement in Investigator's Global Assessment (IGA) and in the Eczema Area and Severity Index (EASI) by week 16 of treatment with tralokinumab compared to placebo, and these improvements continued for most patients through week 52. Improved sleep, itch and overall quality of life were noted for AD patients participating in the studies. Reported side effects included upper respiratory tract infections (common cold) and eye and skin infections, but for the most part these did not cause the patients to leave the study or quit taking tralokinumab.⁴ The majority of side effects happened during the first 16 weeks of treatment and did not continue as patients were on the drug for longer. FDA review of tralokinumab for moderate-severe AD is anticipated in the second quarter of 2021.

Lebrikizumab

Lebrikizumab (Eli Lilly) also targets IL-13, preventing formation of the IL-13R alpha 1/IL-4R alphareceptor signaling complex. A Phase IIb study of safety and efficacy of lebrikizumab was published in 2020 with 280 adult AD patients split between the group who received the lebrikizumab and those who received the placebo.⁶ Phase III trials, long-term safety and efficacy studies and trials in adolescents (12 and older) are currently being recruited.⁵ In this published study,

patients were injected subcutaneously with lebrikizumab at doses of 125 mg every four weeks, 250 mg every four weeks or 250 mg every two weeks. Improvement in the EASI score from the beginning of the study and 16 weeks was observed, as was lessening of itch as early as day two after the start of treatment. Side effects were injection site reactions, herpes virus infections and eye infections, but did not cause patients to leave the study.⁶

Nemolizumab

Nemolizumab (Galderma) targets the IL-31 receptor, which is a receptor on nerve cells and on immune cells called eosinophils that are activated by signals from T cells. Both eosinophils and nerve cells drive itch responses, and eosinophils also interfere with the ability of keratinocytes to maintain a good skin barrier. A Phase IIb study (24 weeks) of safety and efficacy of nemolizumab was published in 2020 with 226 patients split between those receiving placebo and those receiving 10 mg, 30 mg or 90 mg of the drug by subcutaneous injection every four weeks.⁷ All patients remained on their current topical steroid treatments during this study. Phase III trials and long-term trials are currently being recruited for nemolizumab.⁵ Researchers observed an improvement in the EASI score by week four of treatment, with the 30 mg dose being most effective. A decrease in itch was also observed during the study. The most common side effects were upper respiratory tract infection and infections/inflammation in the nose.⁷

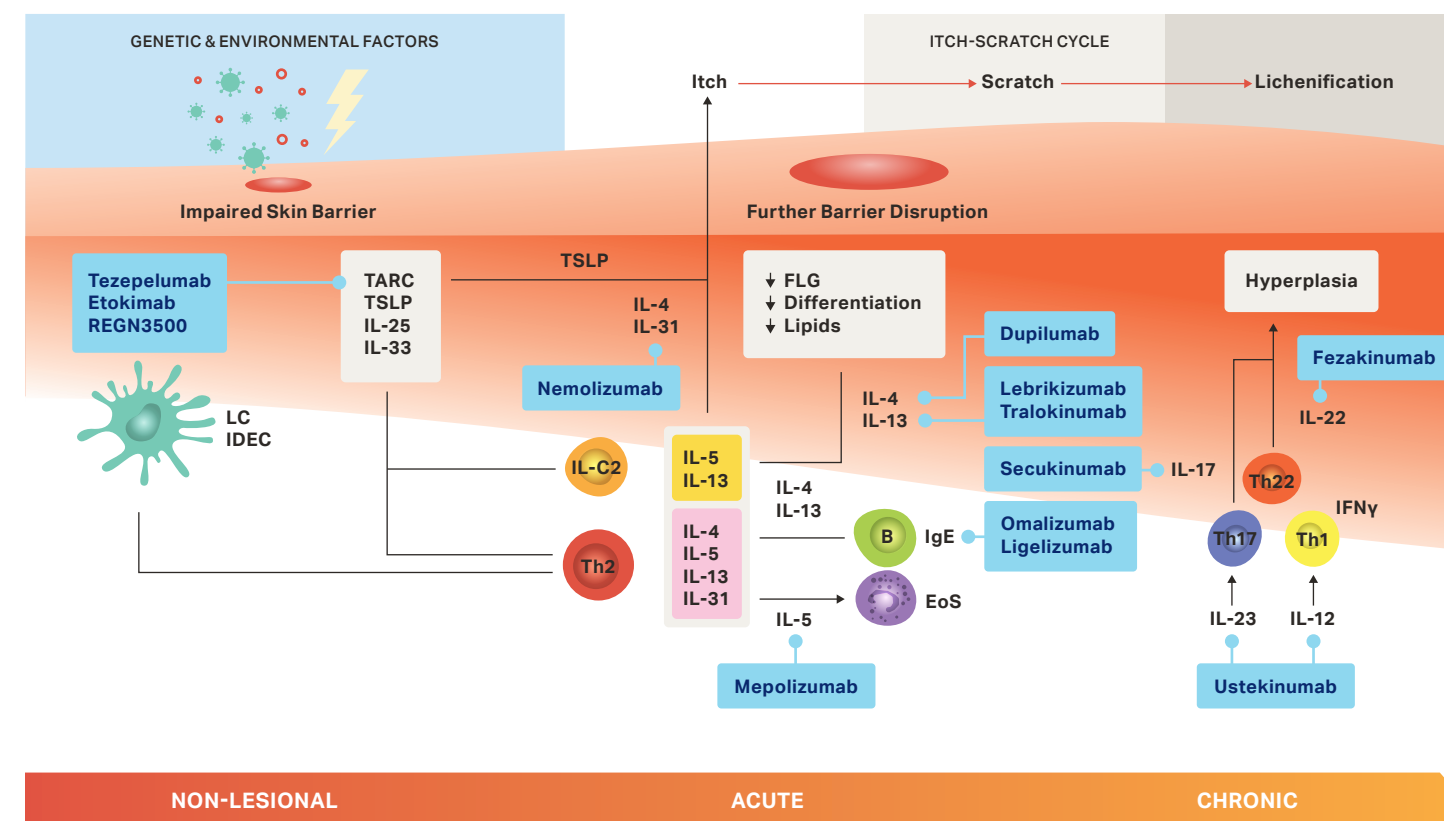


Figure 1: Illustration of the multiple immune pathways and targets for biologics in atopic dermatitis. Shown is a representation of the contributing genetic, environmental, skin and immune system contributors (Th cells e.g. Th1, Th2, Th17, Th22), B cells (B), eosinophils (Eos), ILC2 cells (type 2 innate lymphoid cell), LC/IDEC (Langerhans cells, inflammatory epidermal dendritic cells) to the progression and signs and symptoms of atopic dermatitis. Biologics such as dupilumab and others in development (blue boxes) are shown in relation to the specific immune component they inhibit, such as interleukins (e.g. IL-4, IL-13), antibodies (i.e. IgE) or other cytokines (i.e. TSLP (thymic stromal lymphopoietin)). Figure adapted from 14.

THE FUTURE: HOW CAN NEW BIOLOGICS SUPPORT THE TREATMENT REVOLUTION IN AD?

Current clinical guidelines indicate the goal to manage AD with topical approaches first, if possible, before moving on to systemic treatments due to the increased risk for and severity of possible side effects.⁸⁻¹⁰ Patients and their healthcare providers should work together to review any factors, including the impact of the disease on a person's quality of life, before deciding on the best systemic treatment option, including biologics.¹¹

"We now have over four years of safety data for the first biologic (dupilumab), and there are no new side effects emerging. In fact patients continue to improve with longer-term use and experience fewer side effects over time," said Dr. Simpson.

"We are also seeing benefits beyond skin inflammation like improved mental health, reduced infections and reduced allergy symptoms for some patients. Biologics are not without risk and will likely need to be used in a continuous fashion. That said, I think as the new biologics come on board, we may see more potent responses and less frequent dosing like we see in psoriasis, where 80% of patients can get clear skin with dosing only every three months."



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RESEARCH

While so far only dupilumab has been approved for children 6 years and older (with current trials being conducted for children 6 months to 5 years), there is also hope that some of the other biologics in development may also be able to be used as therapies for children and adolescents.¹² Dr. Guttman-Yassky said, “This is a very exciting time for our patients with biologics changing the treatment paradigm. It is my hope to be able to treat children with AD with these biologics to really modify the disease even from the beginning.”

As new research continues to shed light into the immunological complexity of AD, at different ages and with different racial backgrounds,¹³ the ability to target different and potentially multiple immune response pathways could improve treatment outcomes while minimizing treatment trial and error. Dr. Simpson aims higher. “Biologics that can cure the disease would be the holy grail,” he said, “and we are hoping this is a possibility in the future!”

KEY WORDS TO KNOW:

Monoclonal Antibody — A protein secreted by immune cells that can bind to a target (either another protein, like a cytokine or its receptor) and render it ineffective. Each monoclonal antibody binds to only one protein target or “antigen.” A biologic drug that’s name ends in “mab” is a monoclonal antibody.

T cells — White blood cells of the immune system that are responsible for tailoring the body’s immune response. A subset of T cells, Helper T cells (Th cells) recognize cells as foreign and help other parts of the immune system to respond. Several types of helper T cells are involved in atopic dermatitis and produce chemical messengers called cytokines that drive disease onset and progression.

Cytokines — Small proteins made and secreted by cells of the immune system that send a signal to another cell to respond in a certain way.

Interleukin — A group of cytokines with different functions secreted by white blood cells, including helper T cells. They are abbreviated “IL” and numbered (IL-1, IL-4, IL-12, IL-23, etc.)

Receptor — A protein on the cell surface where a cytokine or interleukin “docks” to start an internal set of signals inside the cell.

TAKE HOME POINTS:

- Over 25 new biologics are in development for treatment of atopic dermatitis. Tralokinumab, lebrikizumab and nemolizumab are the furthest along in clinical trials.⁵
- Growth of new treatments has been fueled by new understanding of key AD immune system disease mechanisms.
- The availability of new biologics will add to the growing options for patients with moderate-severe AD.
- Biologic treatment targets different immune responses, allowing for more personalized treatment. Even if dupilumab was not effective, other biologics might be.

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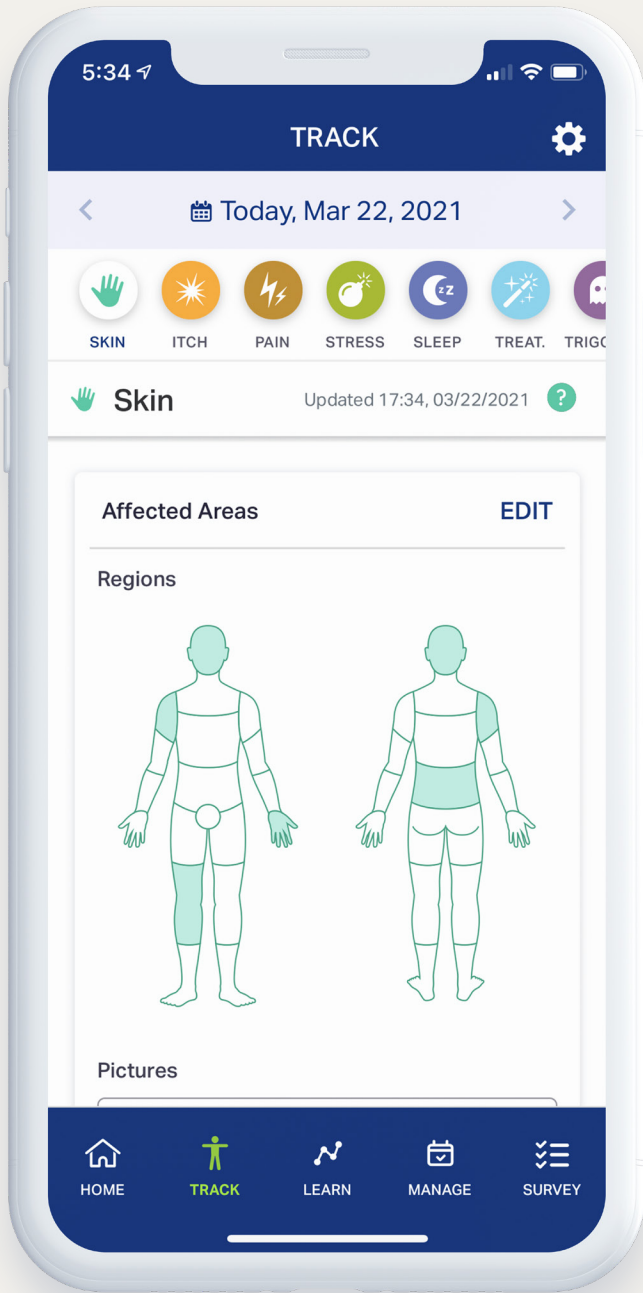
How NEA's EczemaWise app fits into a new era of participatory medicine

by Dr. Lawrence Eichenfield and Dr. Eric Simpson

We're tired of seeing articles that refer to a "silver lining" among the tragedies that befell health care patients and providers in 2020, but the truth is that we learned some things that will ultimately be helpful to us and the practice of medicine.

Long before the Covid-19 pandemic changed how physicians practice under current conditions, healthcare was moving toward participatory medicine, a movement in which patients and caregivers are more actively engaged in care and treatment. But clinicians' inability to readily connect in person with patients this year, coupled with greater familiarity about how technology can help increase wellness, shifted participatory medicine into the express lane.

One condition for which participatory medicine can be particularly valuable and where great strides have recently been made is care of eczema, which more than 31 million Americans have. It is complex, affects each person differently and there is currently no cure. Diet, weather, sleep, stress and topical contact with items like fabrics or metals can all influence how a patient will react. This can be daunting for patients or caregivers who manage a loved one's condition to track for



themselves, much less summarize for their clinicians.

Providing patients and caregivers with reliable information and tools that guide them is critical for participatory medicine, which is why we were excited to test NEA's new app called EczemaWise. Developed with physician and patient input by the National Eczema Association, this app uses a simple smartphone interface that helps patients and caregivers accurately track symptoms, treatments and triggers over time using validated measures. It also provides a quick reference PDF summary that patients can share with providers.

Like regular monitoring for people with diabetes, the app helps patients understand and communicate a much broader story of their disease, which helps us tailor their treatment plan accordingly. A bonus: EczemaWise also connects patients with educational information they can trust.

While there is no doubt patients can and should serve an active role in their care, the process isn't always smooth. Some physicians regrettably resist patients' efforts to become informed and contribute to their care, ignoring important insights or context; likewise, patients can misinterpret or fall victim to dubious information. EczemaWise seeks to bridge this gap.

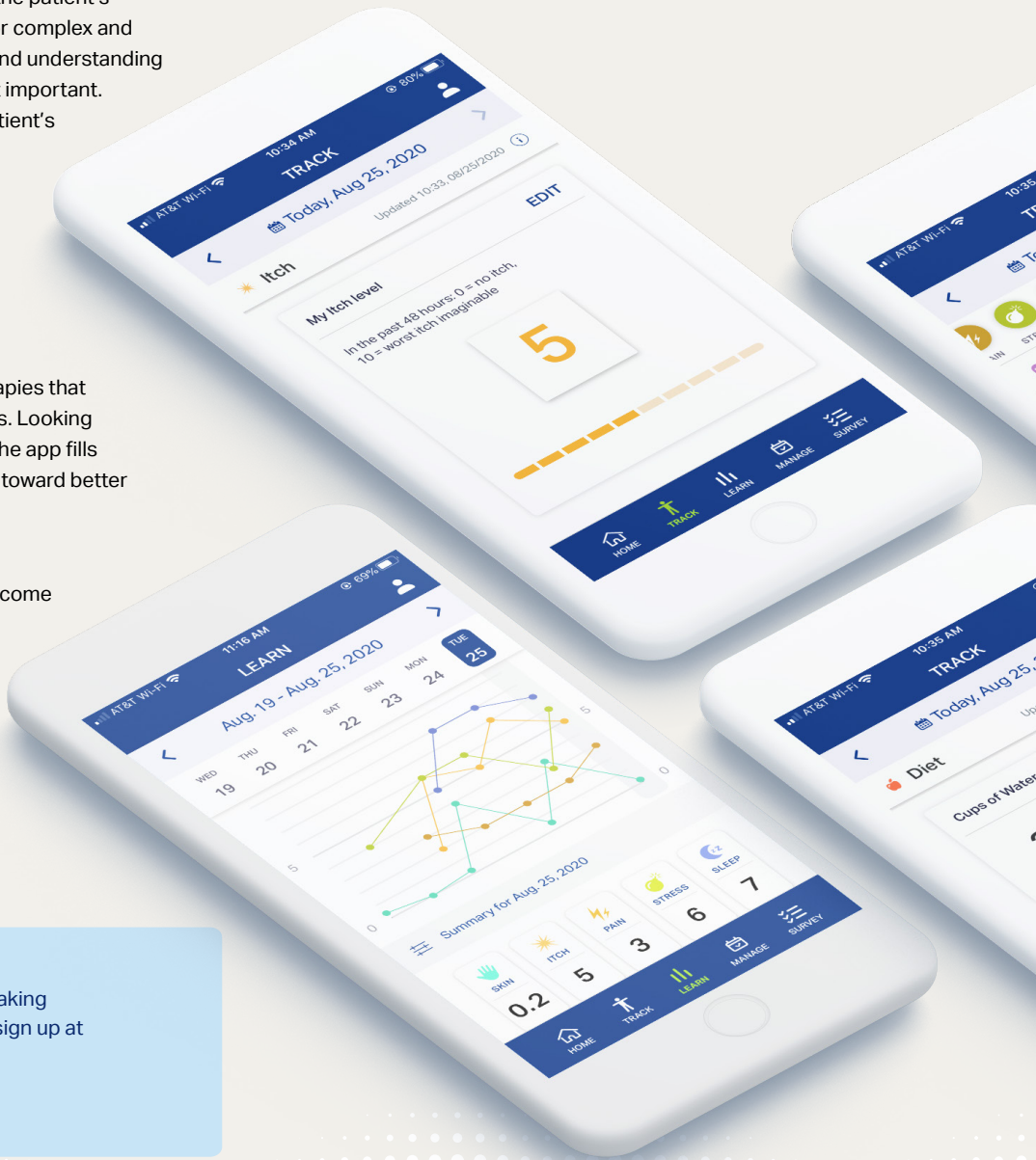
There are countless examples of strong patient-physician collaborations that work well, improving care and outcomes and fostering strong relationships. Typical ten-minute visits with a doctor are not enough to gain a full picture of the patient's condition and any comorbidities — especially for complex and highly individualized conditions like eczema — and understanding what goes on *outside* the clinic is arguably most important. Gaining a complete and thorough view of the patient's status helps doctors understand what course of action is appropriate, if a treatment plan is working and open our eyes to what patients' daily lives are like. These cases tap into what originally motivated many of us to enter medicine in the first place.

After years of stalled progress, the last few have brought an incredible revolution of eczema therapies that provide better control with fewer adverse effects. Looking to the future, the aggregated data collected by the app fills an urgent gap which can help advance research toward better treatments — and perhaps eventually a cure.

This is the type of structured tool that can make participatory medicine a success. We would welcome an app like this at any time, but coming as it did this most vexing year, it really underscores the importance of patients and providers doing what they can, with whatever they can find, to increase engagement and participation with each other. That's a step in the right direction for the future.

Eric Simpson

Eric L. Simpson, MD, MCR, is a professor of dermatology and director of clinical research in the Department of Dermatology at Oregon Health & Science University.



EczemaWise helps facilitate Shared Decision Making between doctors and patients. Learn more and sign up at [EczemaWise.org](https://www.EczemaWise.org).

Lawrence Eichenfield

Lawrence Eichenfield, MD, FAAD, FAAP, is chief of pediatric and adolescent dermatology at Rady Children's Hospital-San Diego and professor of dermatology and pediatrics and vice-chair of the department of dermatology at University of California San Diego School of Medicine.



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COMMUNITY SPOTLIGHT

Alex Dawkins

By Steve Nelson

Alex Dawkins had a dream of serving her country. There was only one catch: she was born with severe atopic dermatitis (AD) and had lived with it all her life. Still, with a medical waiver from her dermatologist in hand, she had no reason to expect that having eczema would slow her down in trying to enlist in the American armed forces — until it did.

"I had met with several recruiters," Alex said. "And one of the superior officers made it seem that I could potentially put myself and others in harm's way if I had a reaction in battle, even though that wasn't true."

Even with her eczema under control, it was clear to Alex that not everyone she met with fully understood her condition; it was not contagious, it was not life threatening and it would not put anyone else at risk. Having eczema — even under control — made the process of enlisting more complicated, more time-consuming. And for some people, it would have been too much to overcome.

The daughter of a determined single mother, Alex was not someone who would give up easily. Her mother had raised her, along with her two sisters, to work hard and to follow their dreams. Alex's mother had always made sure that Alex saw the right kind of doctors, specialists with knowledge about eczema — and by high school she had learned to manage and control her flares.

"I cut out all the negatives," she said. "I surrounded myself with positivity. I started to write poetry. I put everything down on paper. And I surround myself with people who believe in me."

By the time she started to dream of serving her country, she knew how to manage her condition. She also had two important family members who believed in her. Alex's older brother and his wife were both actively serving in the United States Air Force.

"My brother's wife was one of my biggest role models," she said. "I saw her life, and my brother's life, and I thought: that is cool, that looks fun, I could travel — I could make a difference."

"I surrounded myself with positivity. I started to write poetry. I put everything down on paper. And I surround myself with people who believe in me."

During her senior of high school, Alex started talking with different recruiters from the Air Force. She signed up for the Armed Services Vocational Aptitude Battery examination, known as the ASVAB exam. "The Air Force was my first choice," she said, "because that was where my family was serving." In order to enlist, she would need to pass the specific sections of the test that mattered most to the U.S. Air Force: mathematics, electronics, mechanical processes. But it wasn't so easy.

"I had to take the test four times," she said, laughing. "My brother only had to take it once. And you know, it was frustrating. I took time off. I started nursing school. I took a break to collect myself."

She considered trying to join the U.S. Army too. "I had met some pretty fantastic people that have served or are currently serving in the army." But that was when she met the recruiters and superior officers who expressed their reservations about her qualifications based on her eczema.



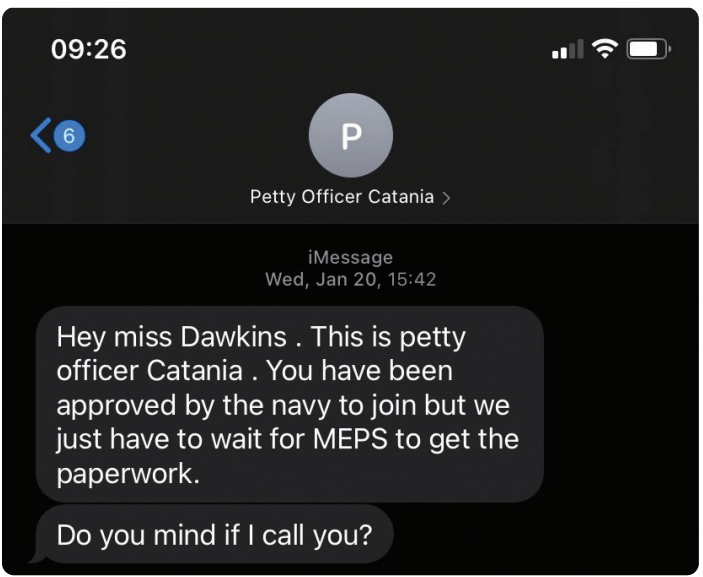
"I had my waiver and everything," Alex said. "I had two different letters, from two different doctors, saying my eczema would not put anyone at risk. I wasn't officially disqualified from the Army, but talking to a lot of veterans and recruiters it would've been a 'no' anyways."

That was her third attempt to enlist. "It was frustrating," she said. "But all that time, my brother told me: keep going, keep going. And I told him, 'I'm nervous. You know, what if I can't do it?' But he just told me: keep going."

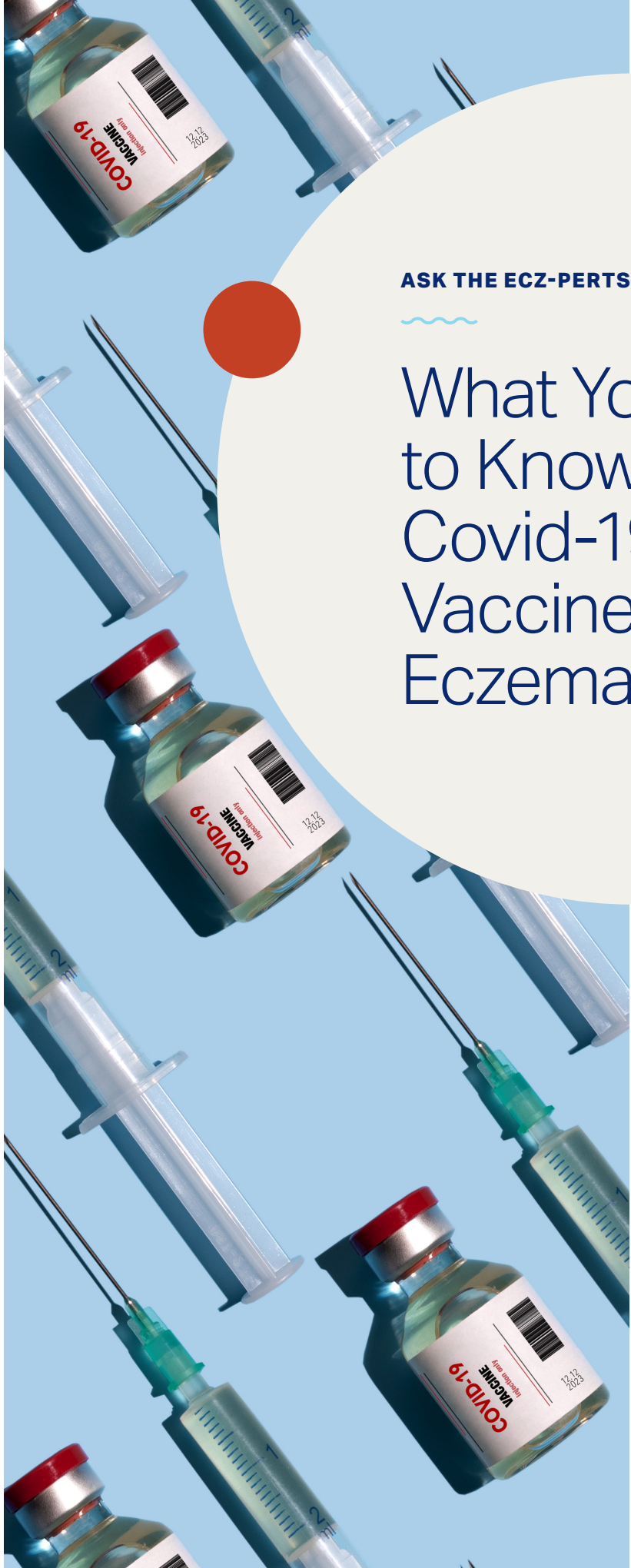
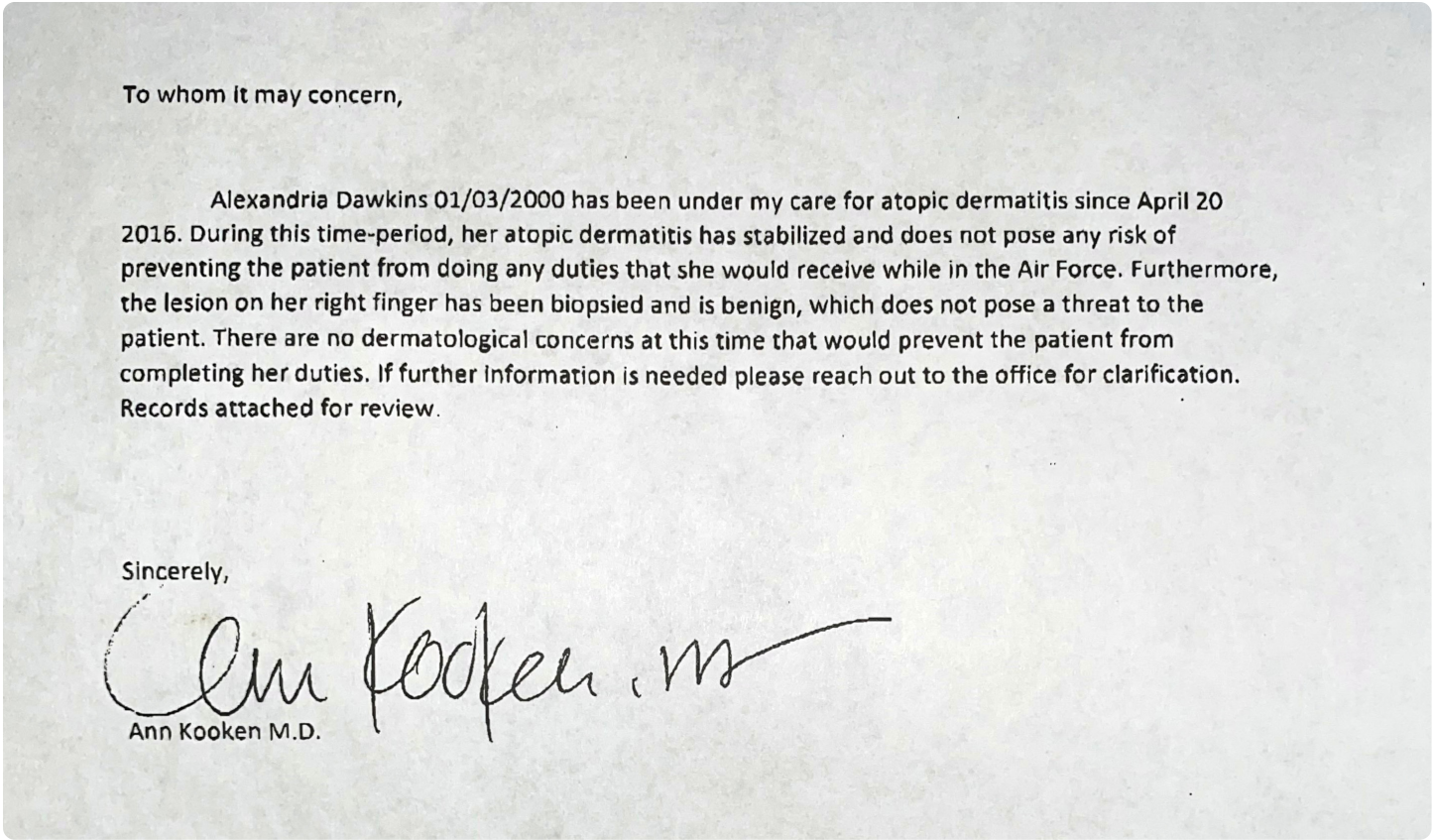
In October of 2020, Alex took the test one last time. And, at last, she passed. Having passed the test, however, Alex didn't realize there was one major obstacle remaining; even though she had been granted medical clearance by her doctors, her waivers would still need to be accepted by the Air Force medical board. And, even after she passed the entrance examination, the Air Force medical board marked a red flag in reviewing Alex's medical report and indicated that that they wouldn't have a topical medication for her to use in battle — enough to disqualify her from joining the Air Force.

When her recruiter called her with the disappointing news, she asked if Alex would be willing to serve in the U.S. Navy. The Navy, according to the recruiter, had different criteria for medical approval than the Air Force. Since Alex's test scores were already high enough, all she would need to do is re-submit her paperwork through a Navy recruiter instead. Eczema would not disqualify her.

"It was only like two, three days later," said Alex. "And I got in."



Alex signed up and now has a three-year contract to serve in the U.S. Navy. Her dream, though realized in a way she had not expected, is about to come true. "I want people to realize," she said. "Life is what you make it. You are your own investment and the world is yours. If you fall, get up and dust yourself off and keep it moving. Take risks and never give up on what you want, always fight for it."



ASK THE ECZ-PERTS

What You Need to Know About Covid-19 Vaccines and Eczema

With the recent FDA approval of three Covid-19 vaccines, from Pfizer, Moderna and Johnson & Johnson, members of the eczema community have raised questions about any potential risks associated with getting vaccinated. While it's always important to discuss and come to a decision with your healthcare provider, the short answer is that having moderate or even severe eczema does not appear to pose any additional risk for getting any of the three Covid-19 vaccines.

We reached out to three medical experts with specific questions from our community about the vaccines and we will continue to add to this story as new information comes to light. If you'd like to submit a question to the ecz-perts, send us an email to editor@nationaleczema.org.

In this edition, **Dr. Andrew F. Alexis, MPH**, **Dr. Amy Paller** and **Dr. Jonathan M. Spergel, PhD** respond to our questions about the first two Covid-19 vaccines and any potential implications for side effects, risks, allergies and treatment of eczema. Dr. Spergel addresses additional questions specific to the Johnson & Johnson vaccine.



Dr. Amy Paller

Dr. Paller is chair of the department of dermatology at Northwestern University Feinberg School of Medicine and a pediatric dermatologist at the Ann and Robert H Lurie Children's Hospital of Chicago.

Does having eczema change the risks or side effects of the Pfizer or Moderna Covid-19 vaccines?

Dr. Paller: No. The only potential issue is an allergy to an ingredient of the vaccine itself.

Many individuals with eczema also have allergies — some have severe allergies. Should I be concerned about getting the Pfizer or Moderna Covid-19 vaccines if I have allergies?

Dr. Alexis: Per the American Academy of Allergy Asthma and Immunology (AAAAI) and the Center for Disease Control (CDC), the following are contraindications to receiving the SARS-CoV-2-mRNA vaccine: "Immediate allergic reaction of any severity to a previous dose of an mRNA Covid-19 vaccine or any of its components, including polyethylene glycol (PEG)."¹

If one falls into the above category, one "should not receive mRNA Covid-19 vaccination at this time unless they have been evaluated by an allergist/immunologist and it is determined that the person can safely receive the vaccine (e.g., under observation, in a setting with advanced medical care available)."¹

Anyone who has an immediate allergic reaction to the first dose of an mRNA vaccine should **not** receive additional doses of either of the mRNA Covid-19 vaccines. Patients with food allergies or other allergies that are unrelated to vaccines or injectable medications may still get the vaccine, but like other patients should be monitored for 15 minutes after administration for any reactions. Patients with a history



Dr. Jonathan M. Spergel, PhD

Dr. Spergel, PhD, is director of the Center for Pediatric Eosinophilic Disease and professor of pediatrics at the Perelman School of Medicine at the University of Pennsylvania.

of anaphylaxis (not due to vaccines or injectable medications) should be monitored for 30 minutes.^{1,2}

Can I have the Pfizer or Moderna vaccines if my eczema is flaring?

Dr. Alexis: Yes, you can. This is not a contraindication as the vaccine is not a live vaccine and therefore cannot infect or spread on the skin.

Dr. Paller: There is no contraindication against getting the vaccine if your eczema is flaring. However, there is a decent risk of having some side effects, and in anyone with flaring eczema these might compound how miserable you feel after getting the shot.

Dr. Spergel: Flaring eczema is not a risk. But I would not give the vaccine in a location with flaring eczema. I would just pick a different location.

How long is it necessary to wait after my Moderna or Pfizer shot before I can have my Dupixent 300 mg injection?

Dr. Spergel: I would wait 24–72 hours due to known muscle aches, chills and fever after the Covid-19 vaccination before having your Dupixent injection.

Do people with eczema classify as having underlying conditions that may move them up on the vaccine list?

Dr. Spergel: Unfortunately, not. The major risk factors are elderly, diabetes, heart disease and obesity.

Are there any eczema treatments that might interfere with the Pfizer or Moderna vaccines? If you are on an immunosuppressive agent like cyclosporine, should you go off to receive the vaccines?

Dr. Paller: There is no increased risk of being on any medication for eczema and getting the vaccine in terms of side effects, as the vaccine is not the virus itself and cannot transmit Covid-19. The only question is whether the immune response mounted after the vaccine will be as strong as possible because of medications taken internally.

We do not think that there is suppression of the immune system from applying anything to skin. We also have evidence that dupilumab (Dupixent), the new monoclonal antibody for eczema, allows an expected response to vaccines (although the Covid-19 vaccine has not been tested previously, of course).

There is some concern about mounting the same response from the vaccine as a healthy person when taking systemic steroids or other medicines that can profoundly suppress our immune responses.

These immunosuppressant drugs do not PREVENT developing immunity but they might REDUCE immune reactivity and protection. That said, studies with methotrexate suggest that with the flu and pneumococcus (no info on Covid-19, of course) there is still good protection. Nevertheless, being off for a short period theoretically could boost that a bit. But this depends on how long one can be off

the drug before flaring.

In the rheumatology world, some are saying "up to two weeks" for methotrexate, and our team recommends just holding the dose for the week after the vaccine and then starting it up again (repeating for the second one). Cyclosporine does not have as long a half-life but still probably could hold for a few days to a week after and then restarting. Some are just not stopping any of them at all, and assuming there will be enough immunity even while on it.

The American Academy of Dermatology has not come out with any recommendation that I have seen. I would probably stop just for two days and restart with cyclosporine (or treat through). For methotrexate, I would skip the one dose after the vaccine.

Is there anything new or different I should know about the Johnson & Johnson "single-shot" vaccine?

Dr. Spergel: The Johnson & Johnson vaccine is a different type of vaccine. The Pfizer and Moderna are mRNA-based vaccines, while the Johnson & Johnson is an adenovirus vector-based vaccine. All three vaccines produce the spike protein. They use very different technologies.

Can I take the new Johnson & Johnson Covid-19 vaccine if I am actively flaring?

Dr. Spergel: I would not get any vaccine in an eczema flaring area. But, if your eczema is flaring in one location, you can get the vaccine in another area that's not flaring.

NEA: The full list of the ingredients in the Pfizer vaccine is available here for review with your physician, in addition to the mRNA: lipids ((4-hydroxybutyl) azanediyl)bis(hexane-6,1-diyl)bis(2-hexyldecanoate), 2 [(polyethylene glycol)-2000]-N,N-ditetradecylacetamide, 1,2-Distearoyl-sn-glycero-3-phosphocholine, and cholesterol), potassium chloride, monobasic potassium phosphate, sodium chloride, dibasic sodium phosphate dihydrate and sucrose. Sourced from the FDA.

The ingredients of the Moderna vaccine are listed here, in addition to the mRNA: lipids (SM-102, polyethylene glycol [PEG] 2000 dimyristoyl glycerol [DMG], cholesterol, 1,2-distearoyl-sn-glycero-3-phosphocholine [DSPC]), tromethamine, tromethamine hydrochloride, acetic acid, sodium acetate and sucrose. Sourced from the FDA.

Lastly, the full list of the Johnson & Johnson ingredients are here: recombinant, replication-incompetent adenovirus type 26 expressing the SARS-CoV-2 spike protein, citric acid monohydrate, trisodium citrate dihydrate, ethanol, 2-hydroxypropyl-β-cyclodextrin (HBCD), polysorbate-80, sodium chloride. Sourced from FDA.

[1] Williams, PV. Messages from the COVID-19 Response Task Force. AAAAI website. January 12, 2021. Accessed January 13, 2021. https://education.aaaai.org/resources-for-a-i-clinicians/task-force-messages_COVID-19

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Dr. Andrew F. Alexis, MPH

Dr. Alexis, MPH, is the Vice-Chair for Diversity and Inclusion for the Department of Dermatology and dermatologist at the Center for Diverse Skin Complexions at Weill Cornell Medicine in New York City. He is the former Chair of the Department of Dermatology at Mount Sinai Morningside and Mount Sinai West.



[3] Pfizer-BioNTech COVID-19 Vaccine. FDA website. Published 1/12/21. Accessed 1/13/21. <https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/pfizer-biontech-covid-19-vaccine#:~:text=The%20most%20commonly%20reported%20side,after%20the%20second%20dose.>

Incyte Dermatology

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Angeline Fowler

Eczema is so much more than a surface condition. It's like an iceberg, with so much more hiding underneath. And the path to healing also lives deep inside.

I'm sharing my story in order to reveal something that took me years to realize: you have the ability to heal within you — you just have to find it.

Itching, pain, burning, swollen, chaffed and irritated is the game I've played for 45 years. As I write this, my eyes are swollen partially shut, I look sunburned, I have a cold pack on my neck, my nostrils and lips are cracked and I'm bleeding through the back of my shirt.

It sounds horrible, but when I was little, I used to wish I had a "real" disorder like leukemia, because people would understand my condition better. Everyone thought I was making a big deal over a "rash," and would compare it to their sunburn, poison ivy or an itchy patch; I felt invalidated and dismissed.

This was something I carried with me well into adulthood. I wish I understood then that I wasn't defined by my skin and that I was lovable, smart, creative and funny no matter what my skin looked like. And if people couldn't see that, that was their problem, not mine.

Mental health is a huge part of eczema. It's one part of the iceberg. When I was younger, mental health wasn't something talked about, let alone in relation to eczema. My own mental health journey hasn't been easy. I wish now I had started therapy earlier, but instead I threw myself into distractions: work, college and community service. The more I did, the more I didn't need to listen to my feelings. I just keep moving, doing and achieving, don't stop. Everyone has their own coping mechanisms, some are healthy, some are not. I didn't even realize mine were unhealthy until it was too late.

Eventually, my body just couldn't keep up. It was like an animated cartoon of a train stopping and all the coaches colliding together — 45 years of feelings hitting me at once. I used distraction and work no differently than a drug addict, to numb the emotional or physical feelings, either directly from eczema or the legacy of eczema.

And a little over a year ago, I got sick — really sick. No one could

figure out what was happening to me, but my body started to shut down. I lost 70 pounds without trying to; I developed tremors and all kinds of weird symptoms, and eventually became suicidal.

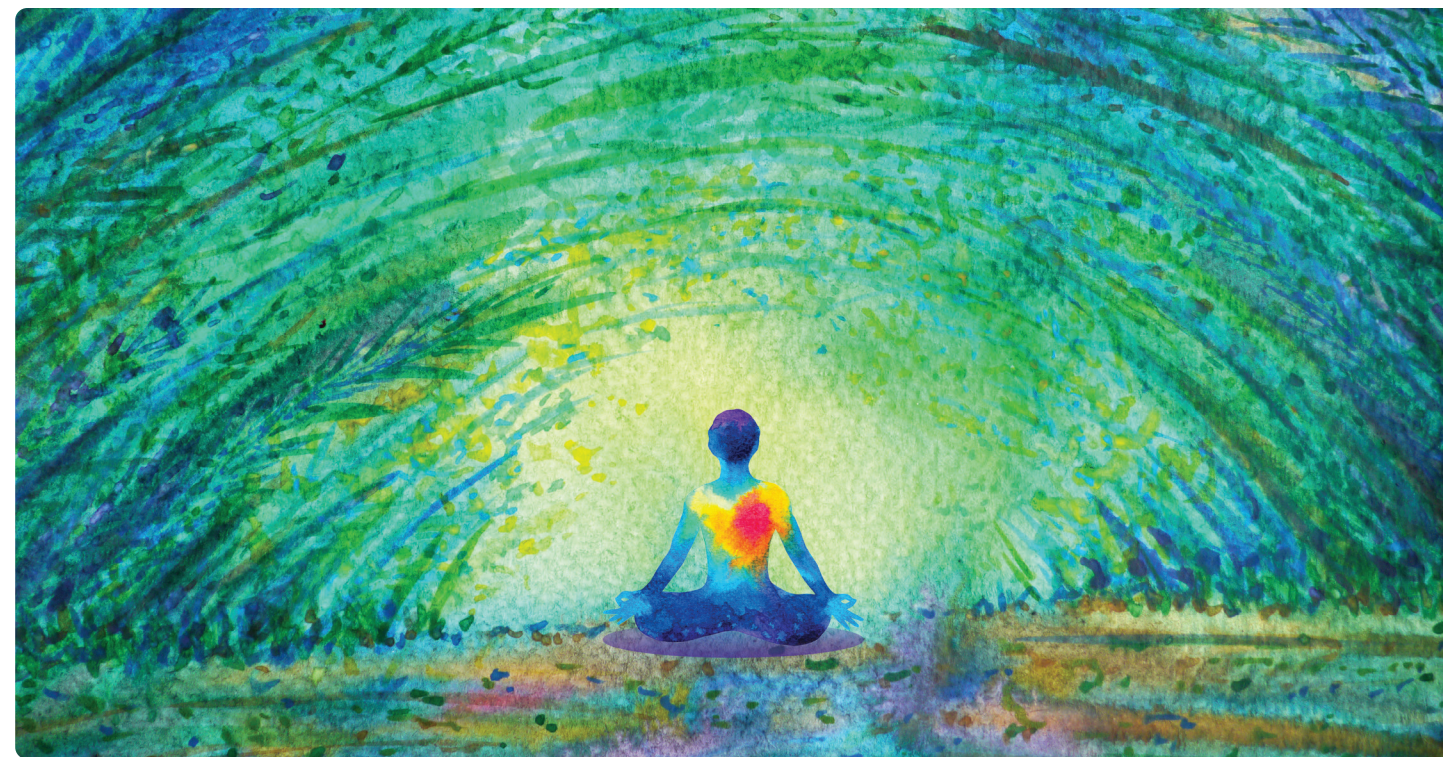
My suicidal ideations led me to a psychiatric hospital that taught me coping skills such as mindfulness, yoga and meditation. But it also helped me recognize the level of everyday stress and anxiety I was suffering from my eczema. Doctors and therapists pointed out that being allergic means that your body is always in a fight-or-flight state, anticipating, worrying, trying to control, defending.

That's before any other stressors; I wasn't aware of the connection between my eczema and my anxiety disorder. Skin inputs key information into the nervous system, so the brain is always on high alert from the extrasensory data received from the skin, not to mention extra thoughts like What can I eat? Can I touch that? Will that cause a reaction? All this can easily overexcite your nervous system, and when you add in steroids, the overexcitement escalates.

I have now been in therapy for the past year, twice a week and I am grateful.

With the right therapist, you feel heard, validated, accepted and seen. They can push back on your thoughts and feelings and it feels more like "aha" versus feeling like you're on the defensive. When you leave the session, you may be sad, but you feel that you learned something, and you made progress.

One of the most helpful things to me was developing an emotion/reactivity scale. The range for mine goes from zen/mindfulness through good; dysregulated, distress to crisis. I check in with myself at least every hour and ask myself where am I? How am I doing? In the past I didn't notice until I was in distress, and by then it was too late. I didn't feel myself ramp up, or I never got myself back to baseline in between periods of stress.



Do you ever find yourself with your shirt or pant legs up, just scratching away, until you bleed and don't remember how the itch even started? Catching it earlier before you get to that point is important and it's the same with your mood. I have a list of go-to activities for each stage. I even have a cheat sheet and signs of each stage on my fridge for my family so that they can help.

Sometimes you just need something quick to stop your spiraling or break up the slide into a bad space. And sometimes, especially if you are dysregulated or distressed you need a prompt from those around you. It's like a reboot.

One of the most helpful things to me was developing an emotion/reactivity scale.

Since Covid-19 started, I have done a lot of walking. My therapist gave me the trick to pick a color and to identify as many things on the walk as you can with that color and write them down at the end. The act of walking and that activity stops your brain from spiraling and enables you to be in the moment. Another one she taught me is something I call "5, 4, 3, 2, 1," which activates all your senses: name five things you can see, four things you can hear, three things you can smell, et cetera. and then tell someone at the end of the walk.

There are so many different types of mindfulness and meditation and, like creams and medication, you must find the one that works for you.

With eczema, I avoid body scan meditation — I need to ground myself in my environment vs my body, otherwise I start noticing my eczema and get itchy and get more anxious.

It took the Covid-19 pandemic and a severe illness to force me to stop and identify what a mental health baseline of calm actually looks like — stripping away all those distractions and old coping mechanisms.

These days, I'm working on anything I can do to help my body — whether that's probiotics, good sleep, eating right for hormone and thyroid stability, mindfulness and meditation. But I am also reaching out to others so that they can learn from my journey and also start to understand that your eczema isn't just about the surface allergen reduction and creams.

For too many years, dermatologists have told us to just put cream on as the answer to eczema, but now there is so much research and investigation into all the new aspects — healing your gut, healing your hormones, healing your mind, and healing your whole body. Your care team is more than your dermatologist now — it's a therapist, an acupuncturist, an OB-GYN, an allergist, a gastroenterologist and so many more. It's also important that you get a regular baseline set of bloodwork for vitamin/mineral levels, hormones, gut, immunology, thyroid — all of which can affect your eczema.

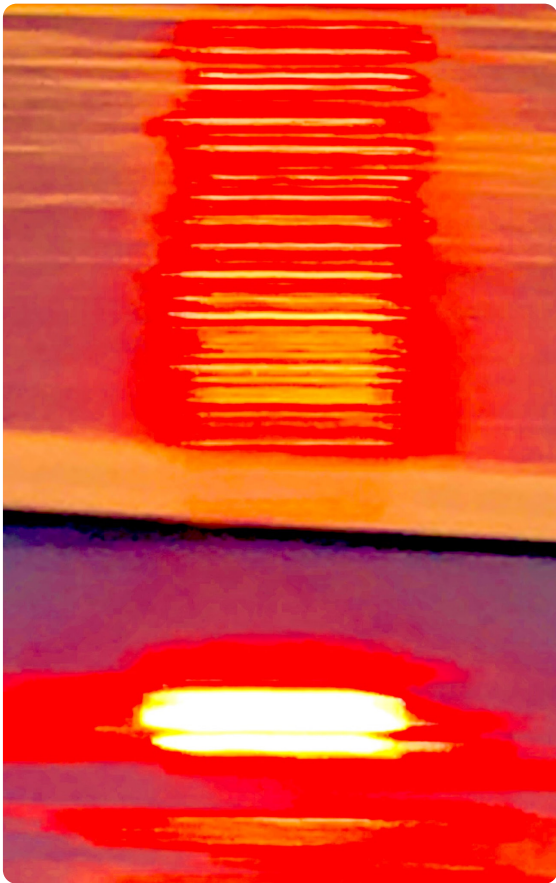
There is the possibility of healing for your body and emotional wellbeing: the right combination of things can help reduce your symptoms — you just have to figure out the right balance.

If you're newly diagnosed, and new to this whole journey with eczema, let me just tell you: hang in there. You are not alone. You can do this.

Original Artwork From our Community



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



↑
Summer Days
Marcela Alatorre-Shirazi

←
My Eczema's Self Portrait
Brigid Jurgens
[@art.bybrigid](https://www.instagram.com/art.bybrigid)



↑
Shadow Blooms
Becky Lewis
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↓
Shaped by Eczema
Megan Thomas
[@meganicolethomas](https://www.instagram.com/meganicolethomas)



IT'S ALL RELATIVE

The Eye Condition that People With Eczema Need to Know About

By Angela Ballard, RN

We typically associate deteriorating eyesight with aging, but for people living with eczema, a serious eye problem can show up even during the teenage years. Here's what you need to know about a condition called keratoconus, including the warning signs that indicate your potential risk and how to treat the condition once you've been diagnosed.

While the causes of keratoconus are not fully understood, it is a known complication of eczema (as well as other conditions) and is related, in part, to vigorous and long-term itching or rubbing of the eyes. Keratoconus occurs when the clear, protective outer layer at the front of the eye (called the cornea) becomes thinner and changes shape over time.

Rather than being round or dome-like, the cornea affected by keratoconus becomes progressively more cone-like and may even bulge from its natural position in the eye. Because the cornea plays a key role in focusing light entering the eye, changes in the shape of this structure can have serious consequences for eyesight and, without treatment, can lead to permanent vision loss. Fortunately, there are treatments that, when started early, can help people with keratoconus maintain their vision and normal lives.






"It's important to catch this problem early," said Dr. Jason Dimmig, an ophthalmologist in Bend, OR, and former president of the Oregon Academy of Ophthalmology. "We don't fully understand keratoconus yet, or why it necessarily happens, but we know that it can progress pretty quickly and we want to catch it and manage it early."

There is not yet widespread data on exactly how many people have keratoconus. Numbers from the National Keratoconus Association vary from one in every 375 to one in every 2,000 people. "It's not that

uncommon," said Dimmig, "but it's not that common, either. The biggest risk factor is rubbing your eyes a lot when you're young."

Indeed, Johns Hopkins Medicine notes things that increase the chance of developing keratoconus: chronic eye rubbing, lasting eye inflammation due to allergies or irritants and family history of the condition.

According to the National Keratoconus Association and Mayo Clinic, here are important warning signs to watch:

-  Blurred vision (perhaps mild)
-  Difficulty seeing at night
-  Sensitivity to bright light or glare
-  Headaches
-  Frequent changes in optical prescription
-  Vision that cannot be corrected with glasses
-  Noticeable eye rubbing

Whether a person's eyes are itchy due to eczema around the eyes or on the eyelids or if the eyes themselves feel itchy, it's important to get treatment from your medical team, including a dermatologist and an eye doctor (ophthalmologist) to control the itch and prevent excessive eye rubbing. When diagnosed early, keratoconus can be better managed so vision can be protected. "There are lots of things we can do," said Dimmig.

Treatments include medications to ease itch and limit rubbing; specialized contact lenses to help reshape the cornea for improved vision and to help prevent eye changes from worsening; a procedure called corneal collagen cross-linking that uses ultraviolet light and a vitamin B solution to help strengthen the cornea; corneal implants; or, for severe vision loss, corneal transplants.

Because keratoconus is often first diagnosed in the teen years, the condition can become quite serious by the time a person reaches their twenties, so it's important for the parents and caregivers of young people living with eczema to be aware of the risks, warning signs and role of early detection and management. Awareness, education and diagnostics can help keep eyes healthy.

Talk to your doctor about how often you or your child should be having eye exams and be sure to tell him or her about itchy eyes, vision changes or sensitivities and any family history of eye problems. If you or a loved one is diagnosed with keratoconus, visit an eye doctor regularly for monitoring and treatment to keep eyesight at its best.

"We don't fully understand keratoconus yet, or why it necessarily happens, but we know that it can progress pretty quickly and we want to catch it and manage it early."

Learn more about keratoconus at NKCF.org.

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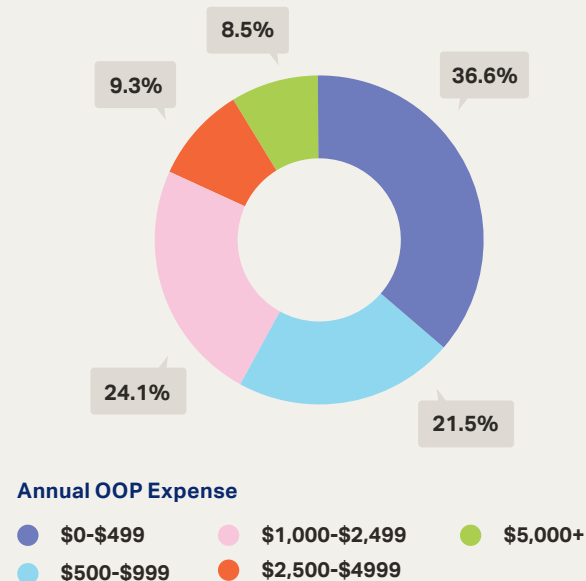
Hong Hu, Research Advisor,
Lilly Research Laboratories

ECZEMA BY THE NUMBERS

Eczema is Expensive:

New Research by NEA Reveals the Out-of-Pocket Costs of Eczema

The financial burden of eczema is high for patients and caregivers.



36.5%

of respondents reported diagnoses of anxiety and/or depression, yet only 14.4% reported expenses for mental health services

People with eczema often deal with anxiety and depression, yet few report expenses related to mental health

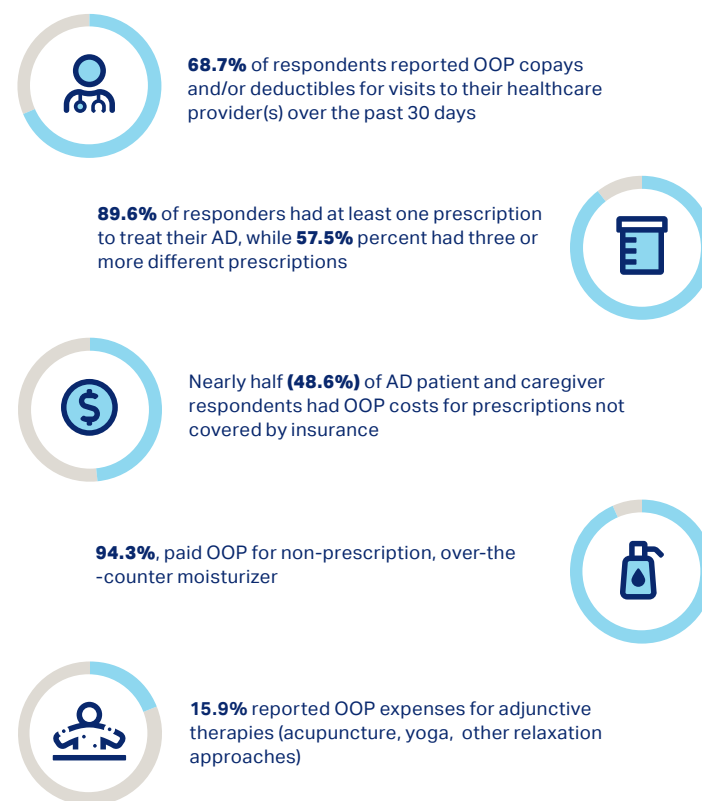
We know living with eczema comes with many costs. But, until recently, we did not know the extent of financial costs that Americans bear out of pocket (OOP) to manage their atopic dermatitis (AD).

The NEA research team set out to fill this gap with a survey of its eczema patient and caregiver community. The findings, analyzed in collaboration with researchers Dr. Raj Chovatiya, PhD (Northwestern University) and Dr. Jonathan Silverberg, PhD, MPH (The George Washington University School of Medicine and Health Sciences), have been published (in part) in *Dermatitis*.¹

This study highlights the real-world costs of eczema and the importance of patients and their healthcare providers creating treatment plans that minimize financial burden while improving disease and quality of life outcomes.

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

Patients and caregivers spend in multiple categories and purchase multiple products — many not covered by insurance — to manage the diverse and unpredictable symptoms of eczema.



[1] Smith Begolka W, Chovatiya R, Thibau I, Silverberg J. Financial Burden of Atopic Dermatitis Out-of-Pocket Health Care Expenses in the United States. *Dermatitis*. 2020; 10.1097/DER.0000000000000715

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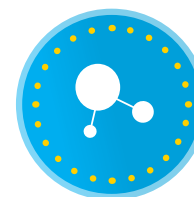


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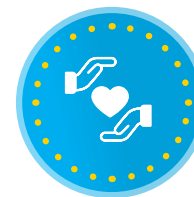
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