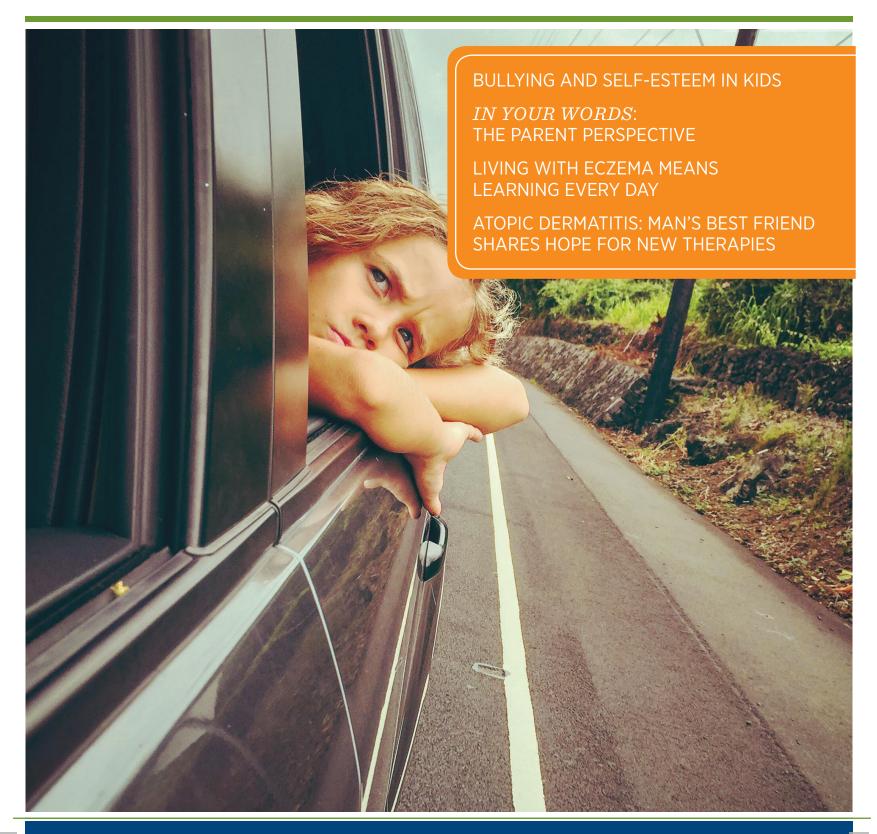


# The ADVOCATE

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#### MISSION

The National Eczema Association (NEA) improves the health and quality of life for individuals with eczema through research, support, and education.





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Everywhere we turn, NEA members, friends and partners are engaging in significant ways to improve the health and quality of life for those with eczema.

This year's Eczema Awareness Month (EAM) is a fantastic example. Kicking off this year's EAM was our sixth annual Itching for a Cure Walk, where more than 200 people participated in raising money for a cure for eczema. Throughout October, over 1,000 people participated in a Start from Scratch Challenge highlighting eczema management tips and dozens more received our Tools for School guide. We closed EAM with record-breaking attendance at our Leaders in Eczema Forum, co-hosted with our partners at the University of California San Francisco (UCSF).

In the last quarter of 2016, a national survey on the prevalence and quality of life impact of adult atopic dermatitis will be conducted, the first of its kind in the United States. The data will provide the necessary evidence to pull back the curtain on this long underserved disease, and aid us in our movement to improve care and change conditions for patients and families. We can't wait to share the results with you!

Additionally, NEA has partnered on a pediatric initiative called "Guidance Document for Industry" that will help define the best practices for including children in clinical trial research for eczema treatments.

Support from community members like you make our work possible. I appreciate the many ways our members and partners have helped NEA advance our long-term goals, including ensuring everyone with eczema has access to the information, treatment options and care they need to best manage their condition.

Whether you've donated to NEA this year or not, I encourage you to make an end-of-year contribution to support our on-going efforts. Every gift advances NEA's mission to improve the health and quality of life for all individuals with eczema.

Thank you for all your support.

Julie Block
President & CEO



# ECZEMA IS A REAL CHARACTER



Image credit: HBO

The HBO mini-series called "The Night Of" is about a complicated murder case set in New York City. It's about the transformation of a young Pakistani-American man from a "nice guy" to a Riker's Island criminal.

It's also about eczema. And how this condition can affect every part of a person's life.

Actor John Turturro plays John Stone, a two-bit unsuccessful lawyer with severe eczema. Stone finds himself defending Nasir Kahn, played by Riz Ahmed, who is charged with the brutal murder of a young woman.

"The Night Of" is based on the BBC series "Criminal Justice," written by Peter Moffat. Moffat has atopic dermatitis (AD) and used his considerable experience with the disease to develop the John Stone character. When writers Richard Price and Steven Zaillian brought the series to the U.S. and amended it to become "The Night Of," they decided to expand the role eczema plays in Stone's life. In a recent interview about the show with The Huffington Post, Price said that eczema became "a metaphor for the frustrations of ... the entire judicial system."

The portrayal of a person with severe atopic dermatitis in "The Night Of" is as honest and sensitive as it is accurate. Viewers who struggle to manage their eczema will recognize some universal themes in the miniseries.

# Eczema dictates what you can or can't wear, regardless of the situation

People with eczema can have skin reactions from certain fabrics and laundry soaps. For some, friction on the skin from shoes or tight jeans can cause flares and pain. People with eczema are advised to simply avoid those fabrics and clothing types. But what if certain types of clothing and fabrics are essential to your profession?

John Stone is introduced often in sandals because the severe eczema on his feet does not allow him to wear closed-toe shoes. This is a source of shame for Stone, as he has to wear sandals in professional situations that require men to be in dress shoes. Moreover, Stone's sockless, red, irritated feet in sandals draw at best, polite questions from others, and at worst, revulsion.

When Stone tries an herbal treatment that appears to calm his skin for a period, the first thing he buys for



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himself is a nice pair of dress oxfords. His joy when he removes the new shoes from their box and puts them on to attend court, is transparent.

# Eczema itch can be all consuming

One of the main symptoms of eczema is itch. According to Dr. Gil Yosipovitch, a dermatologist and member of the NEA Scientific Advisory Committee, eczema is the most common cause of chronic itch, with some 17 million people in the U.S. affected. Dr. Yosipovitch, an expert on itch in humans, says the itch from eczema comes from a different set of nerve fibers than the itch that happens when you come into contact with an allergen such as poison ivy or pet dander. These nerve fibers also may transmit pain, perhaps contributing to why so many eczema patients experience itch and pain together.

Like many people with severe atopic dermatitis, John Stone spends much of his waking hours scratching. He not only employs his nails to scratch but carries around a chopstick for hard to reach places such as his back and his feet. His compulsion to itch overtakes him no matter the situation. We see Stone scratching as he talks to his client Kahn in a jail cell and watch him claw at his chest and face in public and private. No relief and no reprieve from his nerve fibers gone haywire due to his eczema.

# Finding a treatment that works is exhilarating. Losing that treatment is heartbreaking

See John Stone at the drugstore. See Stone standing in front of a shelf filled with dozens of bottles of over-the-counter formulas designed to help with eczema symptoms. See Stone get frustrated, grab a few bottles and slam them into his shopping basket. Sound familiar?

Symptoms of eczema on the skin, such as redness, itching and dryness come from what is happening underneath. People get atopic dermatitis because their immune system goes into overdrive, mistakenly triggered by a combination of genes and the environment. People with severe eczema often cycle though prescription treatments including rounds of steroids, immunosuppressant drugs and light therapy. Some people attempt to manage their symptoms through diet and supplements. But for many people, these treatments ultimately fail and the eczema symptoms return.

John Stone gives us a seat on the rollercoaster ride of finding a treatment that works. He finds an herbalist in New York City's Chinatown, who prescribes him a powder to mix with water. Stone drinks this foul-looking sludge daily and after some time, his skin begins to clear. He is exuberant — his itch is gone, his skin is clear and he can wear nice shoes. Stone talks about his new-found treatment with his eczema support group, where they pepper him with questions about his regimen.

But his clear skin is not to last. Despite taking the herbs as directed, Stone finds his eczema rushing back to cover his body, leaving him back where he started: in pain, struggling and depressed. From the high of finding something that works, to the crushing blow when it stops, John Turturro as Stone, takes us through every emotion in this process.

# Cats are a known eczema trigger for some people — but not all

A sub-plot of "The Night Of" is John Stone's relationship with a cat. The orange and white tabby originally belonged to the murder victim. Stone finds the hungry and lonely cat when looking for evidence at the victim's apartment. He takes the cat to the pound, rescues the cat from the pound, brings the cat back to the pound, and then ultimately rescues the cat again, permanently this time.

In "The Night Of" the cat may be a metaphor for Nasir Kahn and the story of incarceration and redemption. For someone with eczema, Stone's adoption of the cat is a triumph of love over genetics. Or maybe, he was never allergic to cats to begin with.

Not all people with eczema are allergic to cats, although pet dander is a common trigger. The sure way to find out if you're reactive to cats is to get a patch test through an allergist office.

However, before you get that kitten for your kids, research shows that infants and toddlers who have risk factors of developing an atopic disease such as a parent or parents with atopic dermatitis, asthma and/or hay fever should not have ongoing exposure to cats until they are older. Early exposure to cat dander may contribute to the development of atopic dermatitis in children who are prone to the condition.





# Did you know that 1 in 10 children in the US have eczema?

With so many children struggling to live with with eczema, we wanted to hear from our members how eczema directly impacts the quality of life of their school-age children, and their entire family. So this past August, we asked NEA parents and caregivers to reply to a survey about their experiences.

Thanks to the nearly 600 people who responded, we learned that eczema not only negatively impacts their child's health, it also impacts day-to-day life in challenging ways, including at school.

Parents and caregivers who responded shared that:



Eczema has a big impact on my child when at school.

91% My child has trouble at school because of their eczema

54% It's difficult to treat my child's eczema during the school day

50% My child is exposed to eczema triggers at school

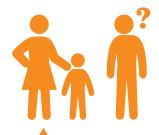
55% My child has difficulty concentrating in class due to their eczema

"He tries to just be a regular kid but it's hard when he's a kid with eczema!"

Other parents and teachers don't understand — or misunderstand — eczema.

56% My child's teacher doesn't understand eczema

53% My child can't easily excuse him/ herself from class to go to the school nurse's office for eczema support



"There are constant stares and questions from people on what's 'wrong' with her skin..."



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# ERSPECTIVE: ECZEMA AND SCHOOL



"It's exhausting for the ones suffering from eczema and [for] the caregivers"

Eczema affects the whole family's quality of life in not-so-visible ways.

57% My significant other and/or I feel guilty that our child has eczema

53% My whole family's sleep is affected when my child's sleep is affected because of eczema

46% The medications and therapies my child needs for his/her eczema greatly impacts our family budget

# We're Here to Help

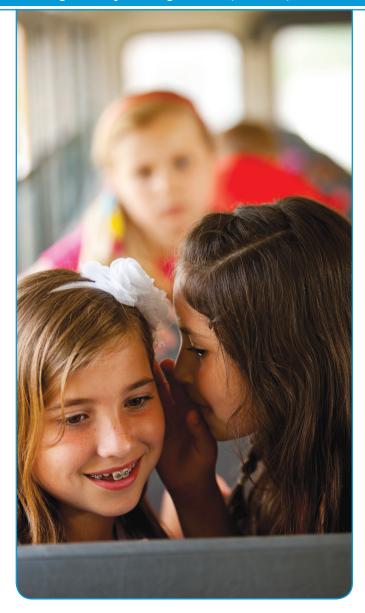
To help support families and individuals with eczema, the National Eczema Association (NEA) has developed a number of online resources from information about basic skin care and managing triggers to an eczema toolkit to help support parents of school-age children. This toolkit, called *Tools for School*, explains the basics of eczema, from what it is to how to best support and empower children with eczema while in school. **There is a guide specifically for parents, and one for educators** — each provide resources and tools to help increase eczema awareness, understanding, and acceptance of children with eczema at school.

*Tools for School* guides are free — we encourage you to share it at home and with your child's educators to help create a happier and healthier school experience. **Download** *Tools for School* at <u>nationaleczema.org/</u>schools.

NEA is also developing other campaigns and initiatives to ensure parents, teachers, and health care providers have the information and resources they need to help improve the health quality of life for individuals — and families — living with eczema.

# BULLYING AND SELF-ESTEEM IN KIDS

By Jennifer Moyer Darr, LCSW, National Jewish Health in Denver, Colorado



Children as young as three-years-old begin to notice differences about others (Chernyshov, 2016) and react to these differences. Sometimes, they are just curious and no harm is intended. Sometimes bullying follows. Bullying can occur in the form of verbal, physical, social or psychological taunts that are harmful, repetitive and involve an imbalance of power. It can occur directly or through electronic means in the form of cyberbullying. Teasing is generally described as more "playful" or "joking" but not necessarily any less hurtful than bullying (Magin et al, 2008).

Teasing/bullying often occurs when someone is viewed as appearing or behaving differently than their peers. Unfortunately, eczema is typically very visible and those with eczema may be identified as being "different" before one even gets to know them.

Many studies have looked at how teasing and bullying based on appearance affects people physically and mentally. Some show that bullying/teasing negatively impacts one's level of self-consciousness, self-image, and self-esteem (Magin et al, 2008). Others identified reduced quality of life and more frequent depression (Halvorson et al, 2014). Still others showed increased anxiety levels and social phobias (Stawser, Storch, Roberti, 2005), feelings of loneliness, and decreased contact with friends (Forero et al, 1999). One study (Fattori et al, 2015) assessed bullying in the workplace and found a substantial impact on quality of life and productivity independent of the individual's underlying medical condition.

Clearly, this isn't true for every person with eczema. At least one study (Absolon et al, 1997) looking at stigmatization found that increased psychological disturbance rates were significantly higher only for the children with moderate and severe atopic dermatitis. Another (Halvorson et al, 2014) found that an association between atopic dermatitis and depression/anxiety/suicidal thoughts was only present when significant itch was also reported.

#### So what can be done?

- Don't overlook the importance of consistent skin care
  to keep the eczema as well controlled as possible. This
  allows one to physically feel better, sleep better and
  itch less all of which positively impacts mood and
  coping abilities. In addition, less visible eczema and
  scratching may help them stay off a bully's radar.
- **2.** Model beneficial ways of engaging others (even when they are rude or insensitive).
- **3.** Practice scenario-based responses so that you/your child have the words/actions necessary to stand up to bullying.



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- **4.** Don't let eczema be the focus of your child's identity. Help your child explore their strengths and become a well-rounded and confident person.
- 5. Involve others. It's never too early to start educating peers, neighbors, teachers and others, about eczema and how it impacts your child. Young children, while understanding differences, are much more accepting once they are educated. Therefore, the friendships established early on will often provide support, encouragement, and education to others throughout your child's formative years. For older children and adults, you may find you have to repeat this in multiple situations; with new coaches, managers, or work teams.
- 6. Ask your child directly if they have been teased, bullied, ostracized/left out, or hurt by others. Children often don't report bullying so if you don't ask, you may not know.
- Get involved with the school and their antibullying curriculum.
- 8. Know your resources. Whether it's accommodations through a 504 plan at school or workplace modifications through Human Resources (HR) there are services and supports available to help you be successful.

At National Jewish Health, we have found that using a multidisciplinary approach changes the focus to the "big picture" of physical health, emotional well-being and impact on family; which increases quality of life for all involved. Creating your own multidisciplinary care team for your child can be very effective. It's important that this team communicate with one another and work together to treat you/your child with an integrated approach. This may take some extra work up front but is well worth it in the long run.



Jennifer Moyer Darr, LCSW is the Manager of Outpatient Behavioral Health Services at National Jewish Health in Denver, Colorado. For the past 12 years she has provided clinical services to children and families living with eczema, asthma, food allergies, and other chronic illnesses.

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# LI KUNG

# Living with Eczema Means Learning Every Day



From left: Jaemin, Li King, Eunice Park and Soomin

"It's kind of amazing and even laughable now," said Li Kung, whose son Jaemin was diagnosed with eczema when he was three months old. "We were two biotech scientists who had no idea what we were in for."

Li and his wife, Eunice Park are parents to Jaemin, 10, and his sister, Soomin, 8. They had no knowledge of eczema when Jaemin was born.

"Although neither one of us have particularly good skin, it turns out there is a history of eczema on both sides of our family. I don't know if we could have changed the trajectory of Jaemin's immune system if we had been more aggressive," Li said. "Even with two educated parents, we couldn't find the research or get a handle on what we could do. The resources just weren't accessible."

Like many families, Li and Eunice began their eczema journey with their primary care physician. And like many parents, they were told to use a hydrocortisone cream on their son's face. They were a little nervous about the steroid but expected it to make Jaemin's eczema go away.

Jaemin's eczema did not go away, however. His treatments escalated from over-the-counter hydrocortisone, to increasingly potent prescription topical corticosteroids. Eventually, they were using the super-potent class of steroids, which is the strongest topical steroid. And even that treatment wasn't effective. The next option would be oral immunosuppressants, such as methotrexate or cyclosporine.

"That was a turning point for us," said Li. "We were concerned about short- and long-term side effects - and it seemed this was a new category of risk and intensity. We also realized that Jaemin was not a normal kid who happened to have eczema," Li continued. "He was a kid who has eczema who can do a lot of things that normal kids do, but who has to change his life to manage his eczema. This will be a life-long journey for him."

Li and his family attended a NEA conference in Boston in 2014. "It was amazing to see how much information really is out there," he said. "For us, meeting other



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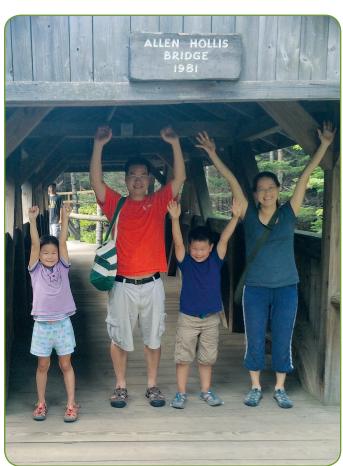
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parents dealing with the same things we're dealing with really helps. But for Jaemin, to meet other kids who know exactly what it's like, and to realize he's not the only one, that's been important." Through that first conference, the Kung family found their current dermatologist.

Li and Eunice decided not to put Jaemin on immunosuppressants. He also went off steroids for one month. "Jaemin's skin went crazy. It peeled. Then peeled again and again. But that process sort of rebooted his skin."

Today, Jaemin has cycles of flares, which they treat with topical corticosteroids when necessary. He follows a daily regimen that includes bathing or showering, moisturizing, wet wraps, wet pajamas, gloves and ice packs in his bed. He listens to special music to relax at night.

Like most kids his age, he sometimes doesn't want to go through his bedtime routine, but he recognizes that if he skips treatments, his skin could flare. This summer he took his regimen on the road to Korea and stuck to his plan



From left: Soomin, Li Kung, Jaemin and Eunice Park

under the watchful eye of his grandmother.

Jaemin's school is supportive, especially when he's tired, having difficulty concentrating because of the itch, or needs help from the school nurse. He has a 504 Plan, which sets out the actions a school will take to accommodate a child with disabilities. Jaemin's plan allows him to take breaks and come to class later if he had trouble sleeping at night.

Li and Eunice rely heavily on their community. "We've been blessed with a great support network," said Li. "One of the great things NEA does is bring together all kinds of people who have been touched by eczema. Eczema never ends and sometimes we really need that connection."

Jaemin is now in fifth grade and loves to read fantasy books, especially about dragons. Li and Eunice are hopeful about the potential new treatments being developed and proud of how Jaemin is tackling the challenges he faces each day.



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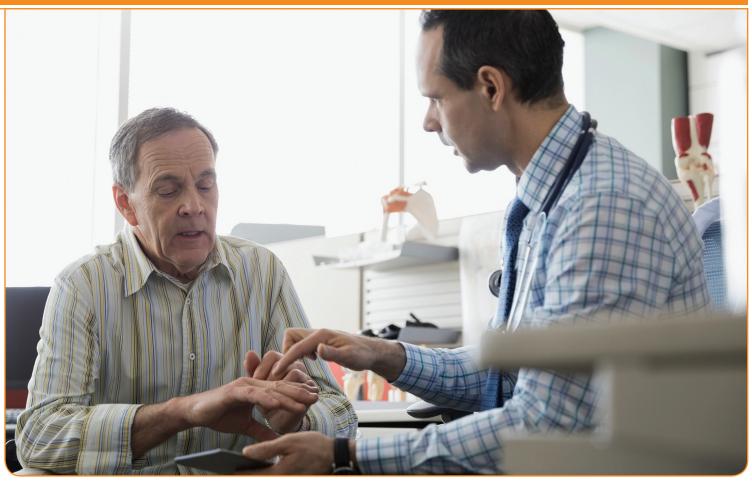
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# **ECZEMA THERAPIES**

New Hope for AD Patients: Crisaborole



For many years there were few treatment options available for people with eczema, including for those with a severe and chronic form of eczema, atopic dermatitis (AD). Today, there are more than 40 new therapies in development, some of which may come to market soon, and new clinical trials are getting underway on a regular basis.

One such new therapy, crisaborole, is a non-steroidal topical that has performed well in multiple phase 3 clinical trials, including with children as young as 2 years old.

As defined by the National Institutes of Health (NIH), a phase 3 clinical trial is one when "the drug or treatment is given to large groups of people to confirm its effectiveness, monitor side effects, compare it to commonly used treatments, and collect information that will allow the drug or treatment to be used safely." Children's bodies can

respond differently than adults', so it's important that this research included children.

If phase 3 trials yield positive results, the next step is typically for researchers to file for approval from the Food and Drug Administration (FDA). Following the positive results of the phase 3 trials for crisaborole, an application was filed with the FDA in March 2016. This has fueled speculation that the treatment could come to market in early 2017.

# What is crisaborole, why is it a big deal, and how does it work?

Dr. Lawrence Eichenfield, professor of dermatology and pediatrics and chief of pediatric dermatology at the University of California, San Diego and Rady Children's Hospital, San Diego, and member of NEA's Scientific



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Advisory Committee, helped explain why crisaborole is exciting, how it works, and what it could mean for people with mild-to-moderate atopic dermatitis.

"It's a big deal because for at least 15 years, other than reformulations of existing medications, there were no new treatments for atopic dermatitis," said Dr. Eichenfield. Many of these medications are topical corticosteroids. These can ease redness and reduce inflammation and itching so skin can begin to heal. While effective for some people, these medications can have side effects, including thinning of skin, particularly with long-term use. "The clinical trials have shown that crisaborole is effective at decreasing inflammation and is well-tolerated with long-term use."

Doctors and researchers do not know exactly what causes AD, but it is believed that genetics and environmental triggers play a role. People with AD may also develop asthma or hay fever. It is also thought that the immune system is a factor — by sending out signals that result in the kind of skin inflammation that causes itch and redness.

Steroids are naturally occurring substances that bodies make in order to regulate growth and immune function. There are different kinds of steroids including anabolic steroids such as testosterone; female hormones such as estrogen; and corticosteroids such as cortisol, which is produced in the adrenal glands. This last type — corticosteroids — have been used for over 50 years in topical medications applied to the skin to treat inflammatory conditions, including eczema. These are called topical corticosteroids. They can be effective for some people, but

not everyone, and can have side effects. They work just below the surface of the skin to reduce inflammation, and thus, the itch and redness.

# How is crisaborole different from corticosteroids?

Topical corticosteroids reduce inflammation in the skin. Crisaborole, on the other hand, may reduce inflammation from happening by inhibiting an enzyme called PDE-4. Enzymes are molecules that cause a biological reaction, like digestion. When the PDE-4 enzyme is blocked, production of a pro-inflammatory protein called a cytokine is reduced — in other words, there are fewer cytokines, that can cause the inflammation that results in eczema symptoms, in the body. Additionally, the recent clinical trials indicate that there are fewer potential side effects associated with crisaborole.

"Currently there is a lot of under-treated AD because of dissatisfaction, and even fear, of existing treatments," said Dr. Eichenfield. "These medications come with potential side effects and in many cases, are not effective. Additionally, there's been a lack of understanding about the impact of this condition. This is a new decade of eczema care. Crisaborole is the first of potential new treatments for AD that bring new understanding of the biology of AD together with treatments that appear to be very safe."

"We also have a new message for people with AD and it's this: there is hope. They do not need to be living with the worst of AD symptoms. We can minimize their symptoms and they can have some relief."



Lawrence Eichenfield, MD: Dr.
Eichenfield is Chief of Pediatric and
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Children's Hospital-San Diego, and
Professor of Pediatrics and Medicine (Dermatology), at the University of California, San Diego
(UCSD) School of Medicine.

# **ATOPIC DERMATITIS 101**



# What is atopic dermatitis (AD)?

AD is a severe form of eczema, which is an umbrella term used to describe a group of conditions that result in itchy, red, and irritated skin. It is a chronic, inflammatory disease that results in red, itchy patches on the skin that can crack and weep. AD falls into a category of diseases called atopic — meaning allergic reaction. It is usually diagnosed and treated by a dermatologist or an allergist.

# Is AD contagious?

No, AD is not contagious.

#### What are the symptoms of AD?

Symptoms of AD include dry, itchy skin that typically appears on the face, inside of elbows or behind knees. However, AD can appear anywhere on the body. Skin may be scaly, bumpy and leathery, or broken, depending on what part of the body is affected.

People with AD are more prone to skin infections and herpes. When it appears on the eyelids and around the eyes, it can result in cataracts, darkening of the skin, and an extra fold of skin under the eye.

# Who gets AD?

Atopic dermatitis usually starts in childhood, but can affect people of any age. People with eczema often also develop asthma and/or hay fever, or are related to someone with these allergic conditions. Children may grow out of AD, however, it can affect some people throughout their lives.

At least 18 million people in the U.S. have atopic dermatitis.

# What causes AD?

We don't know exactly what causes AD but it is believed that genes and environmental factors play a role. People with AD in childhood may go on to develop asthma or hay fever.



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# What are common AD triggers?

Atopic dermatitis can appear, or flare up, when a person is exposed to something in his or her environment. This is commonly called a trigger. Known triggers for AD include exposure to allergens such as pollen, pet dander or peanuts, or by stress, dry skin and infection. Skin irritants such as some fabrics, soaps and household cleaners may also trigger an AD flare.



## How is AD treated?

There is no cure for AD but there are many effective treatments. Flares can be treated with topical steroids, topical calcineurin inhibitors (TCIs) and phototherapy. Systemic drugs such as methotrexate, cyclosporine and mycophenolate mofetil are also used to control flares. New research on what causes AD has spurred the development of new drugs, with more than 40 currently in the clinical trial pipeline.

Systemic and topical treatments in the pipeline include the first biologic drug for adults with moderate-to-severe AD, and a non-steroid topical cream for mild-to-moderate AD patients age 2 and up.

Complementary and alternative treatments for AD that are shown to work include biofeedback, meditation and hypnosis. There is evidence that Chinese herbs and certain supplements, such as probiotics, may provide relief from symptoms of atopic dermatitis.

In additional to treatments, it is important to have a regular schedule of care that includes bathing with a gentle cleanser and moisturizing to lock water into the skin.



# What are some best practices for bathing and moisturizing?

Daily moisturizing and bathing are an important part of managing atopic dermatitis. Here are some tips to remember:

- Take at least one bath or shower daily
- Bathe or shower in lukewarm, not hot, water for 10 to 15 minutes
- Avoid scrubbing
- Use gentle cleanser, not soap, that is dye and fragrancefree
- During flare-ups, limit use of cleansers
- Moisturize within three minutes of bathing or showering
- Use a high oil content moisturizer to improve hydration



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## **EDUCATION**



- Moisturize hands every time you wash them or they come into contact with water
- Schedule bathing and moisturizing before bed to help skin retain moisture
- If using a prescription topical medication, apply as directed before moisturizing

# How will AD affect people's social and emotional life?

The physical effects of AD are evident: dry, itchy, red, and inflamed skin. The emotional effects are not as obvious. People, especially children, may feel singled out for being different, which is exacerbated when the disease limits important activities, such as sports. People with AD must also cope with the lack of understanding from others, along with the unfounded fear that AD is contagious.

AD can also impact family life. Medical visits, time-consuming treatments and alternate sleeping arrangements to manage symptoms affects everyone in the family. Sleep

deprivation is a common side effect of eczema, as the itch/scratch cycle can prevent a good night's sleep. Inadequate sleep can impact academic, social and/or work life.

Physicians, mental health professionals and other health care providers can provide advice on how to manage the stress and other emotional effects that may be associated with AD.

# Are people with AD likely to develop other conditions?

There is growing evidence to show that people with atopic dermatitis are more likely to have other serious conditions such as depression, heart disease, ADHD and epilepsy. These are called comorbid conditions. Talk to your doctor about how your AD might impact other areas of your life.



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# GONE TO THE DOGS: MAN'S BEST FRIEND SHOWS US HOW TO TREAT AD IN HUMANS

Christopher Logas and Peter A. Lio, MD



We share a lot with our beloved canines: our home, our bed and sometimes, even our dinner. But did you know that humans share something else with dogs? A diagnosis of atopic dermatitis (AD).

Dogs with canine atopic dermatitis (CAD) have many of the same symptoms as people with AD, including dry, itchy skin and lichenification (thickening of the skin). Under the surface of the skin, there are also similarities. Both dogs and humans with AD have higher than normal levels of immunoglobulin E, or IgE. IgE is a protein used by our immune systems to fight invaders in our body like bacteria and viruses. Scientists believe that IgE may contribute to our bodies' outsize reaction to allergens in our environment.

Dogs and humans with AD also have similar problems with skin barrier function. These problems cause the skin to be very dry and prone to staph infections. Notably, both groups have lower ceramides (a waxy fat that helps with moisture loss) in the skin; defects in the outer layer of skin called the stratum corneum; and missing enzymes that help dogs and humans metabolize unsaturated fatty acids, which help many cells in our bodies function.

Researchers are looking at filaggrin mutations in dogs

and people. Fillagrin, a natural protein, is essential to the proper functioning of the skin barrier. When this protein changes structure — or mutates — in dogs or humans, it contributes to skin barrier function issues common in AD.

If humans and dogs with atopic dermatitis share many biologic similarities, will treatments that work for CAD work for AD? Current research points to yes.

According to Peter Lio, M.D. and Christopher Logas, dermatologists overwhelmingly focus on treating the symptoms of atopic dermatitis from the "outside in" by restoring skin barrier function and decreasing inflammation through prescription topicals and bathing and moisturizing regimens. For very severe AD, the doctor may also prescribe an oral drug such as cyclosporine.

Veterinary medicine, on the other hand, focuses on an "inside out" approach to treating canine atopic dermatitis. Depending on the severity of the CAD, veterinarians will prescribe oral steroids, cyclosporine and/or high doses of Omega-3 fatty acids.

By focusing on the inside out, veterinary medicine has lead to new treatments in AD. Most notable is oclacitinib,



NEA-Magazine-2016-Q4\_v2.indd 18 11/10/16 10:46 AM a tablet given to dogs by mouth. Oclacitinib is a Janus kinase (JAK) inhibitor, which is a type of medication that block enzyme imbalances that contribute to inflammatory diseases like atopic dermatitis. In dogs, oclacitinib appears to block the cytokine (a type of tiny protein that causes inflammation) related to itch. Both dogs and humans with AD have more of this cytokine present in the body.

The success of oclacitinib in CAD as well as other JAK inhibitors for treatment of rheumatoid arthritis in humans, has led to research of JAK inhibitors for treatment of atopic dermatitis. In particular, the drug tofacitinib, which is being developed by Pfizer. In a preliminary study of AD patients taking oral tofacitinib, all participants showed a decrease in inflamed skin, redness and itch.

Researchers are also evaluating topical tofacitinib in humans with AD. Early research shows a significant reduction itch behavior in mice with atopic dermatitis. These studies also show that a topical application of tofacitinib with oclacitinib in mice may reduce both itch and inflammation.

For those of us with atopic dermatitis, we have more to thank our dog best friends for than just unconditional love and companionship. We can also thank them for bringing together doctors and veterinarians to expand our understanding of how to effectively treat AD in humans from the outside in and the inside out.

Note: The original version of this article appeared in Practical Dermatology and was written by Christopher Logas and Peter A. Lio, M.D.



Peter A. Lio, MD is Assistant Professor of Clinical Dermatology and Pediatrics-Dermatology at Northwestern University Feinberg School of Medicine and Director of the Chicago Integrative Eczema Center. Dr. Lio is also a member

 $of the \, National \, Eczema \, Association \, Scientific \, Advisory \, \\ Committee.$ 



Christopher Logas earned his
Bachelors degree in Biology at the
University of Florida, and is currently
a second year medical student at
Midwestern University.

# WELCOME TIM SMITH!

NEA's New VP, Advocacy and Access



The National Eczema Association (NEA) welcomes Tim Smith as Vice President, Advocacy and Access. Tim is responsible for development and implementation of key initiatives that advance the organization's efforts to increase funding in eczema research, promote eczemafriendly public policy, and ensure people with eczema can access safe and affordable treatments.

Tim has more than two decades of experience in policy research; program administration; health advocacy at the local, state and federal levels; and business planning. Prior to launching his own consulting company, Tim worked in government affairs for health insurance companies where he led several projects for Medi-Cal and the California Managed Risk Medial Insurance Board; and advised the White House and Congress on policy issues.

Tim has served on several nonprofit and public boards and committees, including the state of California's Mental Health Services Oversight and Accountability Commission; the Los Angeles Area Chamber of Commerce Health Council; the Center for Powerful Public Schools in L.A.; and the Southern California Leadership Network. Tim was the recipient of a Coro Foundation fellowship, focused on public affairs and civic leadership.

Tim has a B.A. in linguistics from the University of California, Davis, and an M.A. in public policy from the University of Southern California.



# **NEWS ROUNDUP**



Recent news and articles about eczema, eczema research and treatments, and the lives of people with eczema and their families



## MRSA correlated to eczema?

News-Medical.net, August 31, 2016

Dr. Bjorn Herpers, a microbiologist and chief medical advisor at the Dutch biotechnology company, Micreos, suggests a relationship between staphylococcus aureus, or "staph," and eczema. MRSA is an antibiotic resistant form of the staph infection. Herpers discusses the research that may provide evidence that MRSA staph is an eczema trigger. This finding could lead to the development of new eczema treatments that reduce the need to use steroids.

# Radio host Steve Bailey explores the effects of eczema

BBC News, Radio Sheffield, August 29, 2016

A British radio host, who previously kept his struggle with eczema private, comes forward to share his story. Bailey has dealt with severe foot eczema, infections and terrible itch. The show also features a blogger with eczema, a mother and daughter, and a teenager who feels out of control and ashamed. The show reveals the challenges, both physical and emotional, that people living with eczema face every day.

# The hidden price of childhood eczema

Today Online, August 24, 2016

The incidence of eczema among school-age children in Singapore is rising. This article explores some of the ways in which childhood eczema impacts family finances, quality of life, and physical health for citizens of Singapore. The article stresses the importance of disciplined management of eczema symptoms.

# Topical steroid withdrawal: myth vs. reality

It's an Itchy Little World, August 9, 2016

Dr. Peter Lio and Neil R. Lim, explore some of the myths and realities that surround topical steroid therapy, which has been used to treat eczema for decades. The authors discuss the risks of side effects; topical corticosteroid withdrawal (TSW); and whether TSW symptoms are permanent.

# How fashion helped me come to terms with my eczema

Refinery 29, August 8, 2016

Fashion writer, Bianca Nieves grew up in Puerto Rico, where she struggled daily with eczema and allergies. Nieves didn't want anyone to see her skin, so she covered up with long sleeves and pants in the hot, humid island climate. Today, she has come to terms with her condition and as a fashion writer, she gives recommendations of fabrics, fits and colors for eczema-affected skin.

# Study links severe childhood eczema to sedentary behaviors

Dermatology News, July 18, 2016

A study from the National Survey of Children's Health, reports children with AD are more likely to lead a sedentary lifestyle than those who do not have AD. According to the study, children with eczema were 60% less likely than other children to exercise at least once a week. They also were more likely to spend 5 hours a day watching television, on the computer or playing video games. The study also showed that children who experienced sleep problems were even more sedentary.



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# LETTERS TO NEA AND COMMUNITY TALK



Image credit: HBO

# Reader's review HBO's miniseries, The Night Of

I'm so glad to hear [eczema] getting publicity and showing the truth.

– J.M, Charelston, S.C.

I will be watching it ... I currently have 70% of my body affected by eczema. And customers at work constantly say things.

- A.R., Medford, Ore.

# Your tips on bleach baths

Important! Make sure you're using regular strength, household bleach and not concentrated bleach.

- B.A., Va.

I use this when I have areas of eczema that aren't healing. Works every time.

- P.P., Texas

We use Braggs Apple Cider Vinegar in lieu of bleach.

- R.L. Shelby, Iowa

# Sound off: How eczema affects your everyday life

Just last night my husband had to grab my hands several times in my sleep because I was scratching and it woke him up. Eczema has a huge impact on our lives. A lot of people don't understand or don't care to understand the struggles of others, all they see is horrible red skin and side effects of that red skin.

- A.R., Medford, Ore.

People forget the itch [from eczema] ... destroys the way you think. The pain [you feel] after you have destroyed your skin. ... Your skin is your coat and if the coat doesn't look right then you don't feel right.

— J.A.G., Accrington, U.K.

I have had eczema my whole life. [It was] severe as a child and then it just seemed to become more manageable. In the last six months [my eczema has] become unbearable. I'm covered from my neck to my feet. I try not to let it affect my life, but I feel itchy or sore 24/7.

- K.S.J., New Brunswick, Canada

# How you keep your itch under control

Really keeping on my skin care routine and being careful with fabrics when I'm especially itchy.

- S.E.E.S., Bay St. Louis, Miss.

Wet wrapping. Plenty of well-rubbed in moisturizer afterwards. [K]eep contact with the [allergen] to an absolute minimum ... comfortable top, comfortable socks that minimize contact with carpets, rolled-back cuffs, rolled up hems, remove jewelry, all your hair scraped up.

- M.H., Scunthorpe, U.K.

I'm actually allergic to most OTC moisturizers and lotions, so I've just been keeping up with my routine of hydrating my skin (quick shower, bath, or rinse) and then covering in Vaseline.

-L.Y., Wash.

My 7.5-year-old son has had eczema since birth and I keep it under control mainly by diet:

- Organic everything
- No dairy, corn, soy, gluten
- Limit processed foods, artificial sweeteners and food dyes
- Local bee pollen for allergies
- High-count probiotic w/specific strain for eczema
- J.M.B., Wilmington, N.C. ●

Got something to say about life with eczema? We know you do. Send your thoughts, tips and advice to <a href="rebecca@nationaleczema.org">rebecca@nationaleczema.org</a> or post them on our Facebook page. Posts may be edited for clarity and brevity.



# Scratch Pad

I started to get hand eczema for the first time while pregnant and it increased after I gave birth. I've been soaking my hands in my own breastmilk and it has made the world of difference! My eczema is almost gone. Nothing else has worked like this for me and I wanted to share.

Elizabeth B. Brooklyn, N.Y.

After trying every lotion, ointment and cream imaginable, I persuaded my dermatologist to give me a skin test for chemicals. It turned out that I was allergic to propylene glycol, which was in nearly all the ointments that I was using! No wonder they weren't working, and in many case, made my itching worse! If your topical meds aren't doing the trick, perhaps you are allergic to one (or more) of the ingredients.

Marian F Honey Brook, Pa.

I have found that when I put a combination of Vaseline Petroleum Jelly, lotion (unscented) and medicine prescribed by doctor [...] my eczema improves significantly. I always do this after I take my shower and have toweled myself dry. I also apply before I head outside. I've noticed that this works better when you do it all year-round.

Maria G. Long Island City, N.Y.

I wear cotton gloves under vinyl gloves for ALL work around the house and yard. I use Vaniply Ointment under the cotton gloves and it keeps my hands from drying out. The ointment is thick and soothing, even on cracked skin. On severely broken skin, I put the ointment on and wear just the cotton gloves. Some mornings, doing this treatment while driving to work is enough to get me through the morning without scratching and bleeding at my desk.

Kathy J. Columbus, Ohio



# SCIALCIPACI

My son was born with what the doctors call "allergic skin." He is two years old. [...] What seems to work best for him is Cetaphil. They have cream washes and lotions that are age-appropriate for him. We usually pair the Cetaphil lotion with a layer of Vaseline on top to hold in as much moisture as we can. Long pants, shirts, and socks also have been a benefit to him because they help lock in moisture for longer periods of time.

The most recent thing I'm "testing out" is coconut oil. I mix coconut oil and 100% raw shea butter to make a creamy blend. I usually apply it at night because it is very oily. When [my son] wakes up, he has smooth skin, and more importantly, the spots are not red and dry anymore. Since the coconut oil makes his eczema less red and dry, there is no broken, bleeding skin!



Madeline M. Piscataway, N.J.

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The recommendations in Scratch Pad are those of the contributor and do not imply endorsement from the National Eczema Association. The information in Scratch Pad is not intended as medical advice. Always consult your health care provider before starting a new health treatment, diet or fitness routine.

Visit the Scratch Pad section of our website to share tips and tricks along with a photo of yourself: nationaleczema.org/living-with-eczema/scratch-pad/share-your-eczema-tips



# NEA SUPPORT NETWORK



Cynthia Kim and Dr. Robert Roberts were recognized at this year's Itching for a Cure walk for their service to eczema patients in Southern California. Cynthia started NEA's Los Angeles support group seven years ago when her daughter was diagnosed with eczema and she could not find a support group in the area. Her daughter's physician, Dr. Roberts, mentioned that he was thinking about starting a NEA support group, and a few months later, they launched NEA's Los Angeles support group together. The support group meets several times a year at UCLA. It regularly features speakers who address various topics of interest to eczema patients, and Cynthia and Dr. Roberts attend every meeting.

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This year's Itching for a Cure walk which took place on October 2 in Los Angeles raised funds to support critical research. Together we are stepping toward a cure for eczema.

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