

## Kacey Jenkins' Story

### Caregiver

*“Too often, parents and patients are made to feel guilty for wanting to try new or nontraditional treatments when existing options aren't working. We're at the mercy of doctors who aren't trained in eczema and don't understand how it affects different people. Even when we've done all the research and can clearly explain what risks we're willing to take we still don't have the ability to make those decisions on our own.” -Kacey Jenkins, Caregiver*

As a Texas public school administrator and special education coordinator, Kacey Jenkins is no stranger to parental advocacy. She has seen and helped hundreds of passionate parents go to bat for their kids. But she gained a whole new appreciation for just how tenacious parents need to be to protect their children when her youngest daughter, Chayse, started experiencing the effects of eczema. Chayse's older sister Natalie had never had allergic reactions before, so when odd markings began appearing on Chayse's body as an infant, it blindsided Kacey and her husband, Craig. Told by their pediatrician that it was ringworm, the Jenkins took the incorrect diagnosis at face value and gave Chayse the prescriptions, even though the label said, “*not for patients under 18,*” which seemed like a red flag. When the patches on Chayse's skin didn't go away, their skepticism grew. For the next few years, as Chayse became a toddler, her symptoms were so bad that the itching and scratching would keep the whole family up at night and cause Chayse to cry uncontrollably and bleed through her sheets.

The Jenkins family faced a lot of challenges – including conflicting advice from different pediatricians, specialists who wouldn't see patients younger than three years old, friends trying to be helpful who recommended this amazing scrub or that amazing cream, and doctors who knew very little about eczema, much less how it presented on the skin of multi-racial individuals like Chayse. Taught not to challenge medical professionals, Kacey and Craig ultimately agreed to put Chayse on a round of oral steroids to see how they worked. As it turns out – not well.

It wasn't until Chayse turned three that the Jenkins were able to find something that started to relieve her symptoms – a mix of compounded medications and dietary changes. Kacey's research helped point the way, but she often felt like Chayse's doctors were more roadblocks than allies in the family's search for better care and treatment. Even though Kacey had always thought of herself as an advocate, she had to find her voice in new ways and learn to assert herself as the person most knowledgeable about her daughter.

Now nine-years-old, the flare-ups still happen, but with Kacey's help, Chayse has embraced the idea that eczema is what IT is, not who SHE is. Kacey and Chayse have what Kacey refers to as “a weird trauma bond” created through their shared experience with eczema. “More than skin deep” means a lot of things to the Jenkins family – physical health, mental health, costs (both financial and emotional), community, and compassion. What gives them hope is the pace of change and the possibility for more personalized treatments in the near term. And what they really want to see is more research into how different treatments affect different populations differently.

