

## Akilah Evans-Pigford's Story

Caregiver, Former patient

*"My hope for the future is more — more treatment options, more accessible, affordable drugs that meet people's needs where they're at, and more research, especially involving people of color. Eczema may be a common disease, but it's not one thing, and every case is different. We need to treat each person holistically, based on their unique symptoms and experiences."*

- Akilah Evans-Pigford, Patient and Caregiver

Akilah Evans-Pigford was diagnosed with eczema as an infant. Her parents noticed she had adverse reactions to breastmilk when she was a few months old, including a flaky rash behind her ears and in the folds of her skin, and asked their doctor for advice. Topical treatments were most available at the time, so her parents started using hydrocortisone creams, bath soaks, and other elixirs on Akilah at home. Her symptoms responded well, keeping symptoms manageable through childhood. As Akilah grew, her skin became less and less irritated until she grew out of her eczema altogether during puberty. So, when she had her own child, a son, who developed a similar-looking rash a few months into breastfeeding, she knew what it was and assumed he would have the same "textbook" experience she had. And he did – until he turned five.

Akilah's son Miles began experiencing contact dermatitis from the cleaning products at daycare, and his "textbook" rash exploded into painful, itchy patches covering his arms, legs and back that wouldn't go away. Akilah had more therapies at her disposal than her parents did, not just over-the-counter treatments but prescription medications and oral steroids too, and she tried them all. Nothing seemed to help. He was miserable, she was miserable, and for a time, their lives were punctuated by regular doctor and hospital visits to try and find relief from his severe infections. Akilah felt their doctors didn't really listen to them or take time to answer questions before writing a new script and rushing them out the door. Some were even condescending. So, Akilah turned to her family and other patient families for support.

Miles' elementary school experience was scarred by bullying, name-calling, social isolation, and constant discomfort. The quality of life for both mom and son was dismal. He was hurt and screaming in pain much of the time, asking Akilah why God was punishing him and if it would be easier if he weren't around. She knew she had to fight, to be his advocate and his voice, so she implored his dermatology team to find other options. They told her about stronger drugs that were used for other conditions, like cancer, which might help him, but which came with risks of serious long-term side effects. And he wouldn't even be able to try them, they said, unless he tried other medications first and "worked his way up." Akilah knew they needed another way.

During one of their many visits to Children's Hospital of Philadelphia (CHOP), the head of dermatology happened to be on clinical rotation with Miles' dermatologist. Akilah took the opportunity to share her frustrations with both doctors and make a case for exploring a different, more personalized approach. That's how she learned about the clinical trial for Dupilumab, the first biologic medication approved by the FDA for moderate to severe atopic dermatitis. Miles was enrolled shortly afterwards. His reaction was almost immediate. Within a few days, Akilah noticed changes she described as "a snake shedding its skin."

Akilah and Miles know that reactions to medications can change, but at least for now, his symptoms are in remission, he has regained his confidence, and he now has a core group of friends with whom he plays rugby and football, something he could never have done before. Even though there are still occasional flares and itches, it's nothing like before. Their hope is that more—and more personalized treatments—will be developed so that everyone suffering has access to an option that works for them.