

Hi, my name is Aidan Abbott, I'm 19 years old and from Slinger, WI. After years of appointments with specialists at Children's Hospital, a geneticist diagnosed me with X-linked Hypohidrotic Ectodermal Dysplasia (XLHED). This disease affects my skin, hair, nails, sweat glands, & teeth. My skin is extremely sensitive and rashes form easily. My nails are sensitive and my sweat glands don't function properly and therefore makes it hard for me to regulate fevers causing me to overheat easily.

I believe that skin is one of the most important body parts as it protects the other parts of my body. If my skin is not taken care of properly with my daily regimen of creams and medications, it can break down easily and can lead to infection which could cause me to end up in the Emergency Room to control my fevers.

My dermatologist knows my unique medical history, and I strongly believe that they should be making the decision on what treatment or therapy would work best. It's crucial that I receive the right therapy or treatment in an expedited manner rather than trying multiple options that aren't effective, because healthy skin protects me from having secondary health issues like open wounds or infections that will lead to fevers, overheating, seizure & hospital visits. An effective therapy is important to reduce or eliminate secondary health issues and unneeded costs. Adding guardrails to step therapy protocols would preserve a physician's right to make treatment decisions in the best interest of the patients like myself.

One of my personal passions is to raise awareness, educate, and work with providers and members of Congress to increase access to care and treatments. My family currently sees dermatologists in Wisconsin and my youngest brother Lachlen who has Autism and eczema has a 6 month wait time for his initial appointment to see a dermatologist. Since he is non-verbal, he cannot tell us the pain and issues he is experiencing and therefore it's important that he has timely access to dermatology specialists and treatments. In my opinion, Congress should find innovative ways to fund medical research, increase access to treatments, and ensure that there is transparency amongst the Pharmacy Benefit Managers (PBMs). Taking action and allowing for transparency, will in-turn allow patients needing dermatology services to be treated in a timely manner while receiving life-changing treatments at a fair price. Please support legislation that will remove the burden of costs to patients and will help Dermatologists provide the best care to families like mine. Thank you for your time. I am counting on your help. Please reach out to me at any time. -Aidan

