

Lauren's Story

Resilience, Empathy, and Advocacy



Me, aged 2 and 1/2 — **around the time of my official diagnosis.** My parents figured I would have the condition, but now it was official on paper!



Taken **about a month before my first surgery**, aged 8. At this point, you could **clearly see the bending of my left arm** (this is as flat as I could lay my arm to my side), while my right remained straight.



About to go in for surgery. My comfort item, a **Pooh Bear** that I got for my first birthday, went EVERYWHERE with me. He actually made it through my college years before he turned into rags! Nevertheless, **I was told that he was laid to my right side the entire procedure and woke up in recovery with me.**



Leaving the hospital after a 4-day stay, complete with my first severe allergic reaction to medication and a heavy fear of even looking at my arm or bandages. I'm pretty sure I kept that sling on for over a month because I was terrified to see any blood or skin. **It took a while for me to look in the mirror and not cry.**



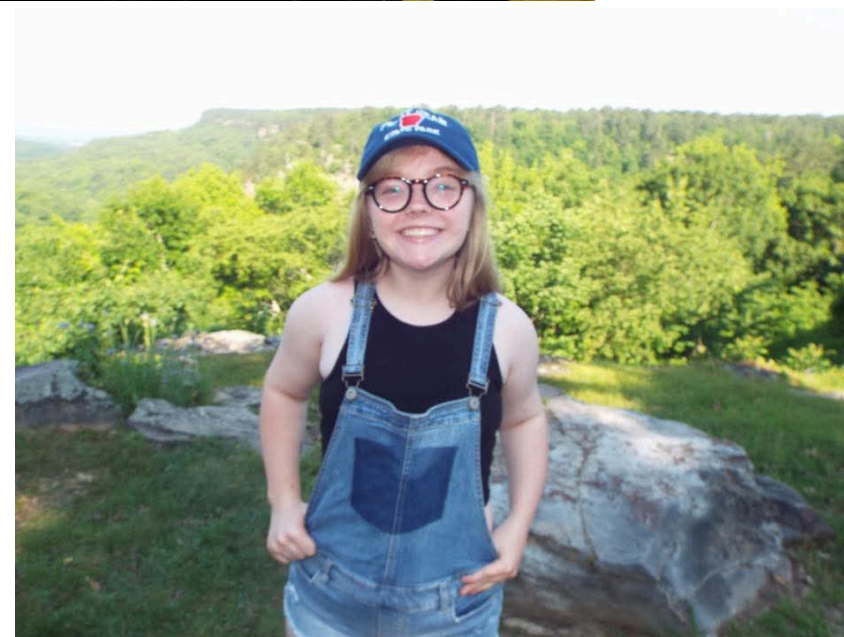
Finally OK with seeing the fixerator on my arm. Celebrating my 9th birthday in the photo, **less than 2 months out from surgery.**



The camera crew coming to film me for Good Morning America! In the right corner you see Tom Bonner, a retired executive producer from one of central Arkansas's news broadcast stations. He was over media production at ACH and chose my story to tell.



I only have one photo from my leg surgeries, as recovery was very difficult. This was one of the first moments I was able to stand on my own after being in the bed and wheelchair for a month and half. You can see the big, blue heavy braces I was required to wear around the clock (except for bathing). I couldn't put on pants, so I lived in sundresses that my grandmother picked up from Walmart.



This was in the summer of 2017, just before I had the golf ball-sized tumor removed from my pelvis & could finally sit down with ease.



Almost 10 years out from any procedures related to MHE. This was actually my headshot I got **taken at Global Genes' Week in RARE** last October

Thank you for sharing your story, Lauren! ❤️

For more resources like this check out **MHELS.org**