

Chloe's scary disorder: I THOUGHT MY CHEST WAS GOING TO EXPLODE!

REAL GIRL CHLOE ON OVERCOMING A CONDITION THAT LEFT HER BREATHLESS.

Chloe Fernandez was jumping on the trampoline at her friend's house, when suddenly, she was sent into panic mode. Her chest was heavy and her body was trembling. Chloe knew instantly that something was terribly wrong. "I got off the trampoline and my chest felt like it was going to explode," Chloe recalls to J-14. "It was hurting, burning and my heart was beating so fast. I really thought I was going to die."

I COULDN'T WALK OR MOVE.

The reason for Chloe's sudden health scare? She was born with primary ciliary dyskinesia (PCD), a rare disorder that blocks the body's airways. Even though people with PCD look perfectly healthy on the outside, they are more likely to develop chronic respiratory infections and often have extreme difficulty breathing — which is exactly what happened to Chloe during that terrifying moment on the trampoline. "I couldn't walk or move," Chloe remembers. "But I got enough energy to call out for my mom." Thankfully, Chloe's mom knew exactly what was happening and sprung into action. "She came running and gave me a treatment on my nebulizer, which administers my medication in a mist, but I was still unable to breathe," the New Jersey native explains. "She drove me to the ER and I was hospitalized for over a week. It was such a sad reminder that I can't do 'normal' things that other people can do."



It took doctors six years to properly diagnose Chloe.



Chloe stays positive through painful treatments.

I'VE FOUND MY NEW NORMAL!

As frightening as the trampoline incident was, Chloe knew she couldn't let her PCD scare her away from good times with her friends; she just had to figure out how to do fun activities her own way. "I used to feel bad about missing out on 'normal kid things,' but there are so many other things I can do," Chloe says. "I have learned that 'normal' is what you make of it." Even though Chloe's PCD has left her



In 2017, Chloe won the WebMD Health Hero Advocate Award. "Living with a disability doesn't mean I am incapable of making a difference," she says.

hospitalized over 100 times, she says her friends strive to make sure she doesn't feel left out. "My friends have never treated me different," Chloe says. "They know of my condition and what can affect it, so they are very mindful of doing things that I can participate in that will not stress out my lungs."

Support is especially helpful when Chloe has to deal with the side effects of her disorder. "The embarrassing part of my treatment is when I have to do my nebulizer in public," Chloe confesses. "When I use it, I feel like people are judging me or are trying to stay away from me. The looks on their faces tell me they are afraid to catch something from me." But that couldn't be further from the truth, which is why Chloe has made it her mission to educate others about PCD. "It's important for me to share my story with other young people because PCD is such a rare condition and knowledge is so important," Chloe insists. "You may not see our illness on the outside, but we are fighting battles daily."

"I want to shed light on living with an invisible illness," Chloe says.

COURTESY OF CHLOE FERNANDEZ, IN REDDING, CALIFORNIA

FILLING BOOKSHELVES WITH PCD AWARENESS

Unwilling to be slowed down, Chloe has worked as a model, actress, advocate, motivational speaker and author! "I never set out to write a book," she admits to J-14. "I was in the hospital library one day and I wanted to find a book about PCD from a kid's point of view, but I couldn't find one!" So at the age of 8, Chloe decided to write her own. "In my book *PCD Has Nothing On Me*, I talk about the struggles of living with PCD and how I cope with not being able to do all the things that my friends can do," Chloe says. "I wanted to let other kids living with PCD or any other kind of chronic illness know that they are not alone." Want to learn more about PCD and Chloe's journey? You can check out her book at Barnes and Noble, Amazon or on her website, www.ChloeRFernandez.com.

