Keilani's Story

From the time she was a kid, Keilani Lime suffered more bumps and bruises than most. An avid soccer and basketball player, she always seemed to be injuring one limb or another — a broken finger here, a dislocated shoulder there. Her doctors just thought she was just accident-prone, never imagining that her ever-growing list of maladies was actually a sign that something was seriously wrong.

In her 20s, she stumbled into a run of mysterious and seemingly unrelated health issues that bewildered one doctor after another. It was only after several years and countless surgeries that an underlying culprit was finally discovered. In 2021, Keilani was diagnosed with classical Ehlers-Danlos syndrome.



EDS is a rare, genetic connective-tissue disorder that affects, well, everything. In short, Keilani's body doesn't produce collagen correctly. Collagen is the glue that holds your body together. If it doesn't work, it causes all kinds of problems, from the sort-of funny (stretchy skin, extra bendy limbs) to the annoying (skin that bruises easily, joint dislocation) to the downright scary, like organ prolapse.

In the past three years alone — basically since she turned 30 — Keilani has endured well over 50 surgeries and procedures, including bilateral hip replacements, brain surgery, spine surgery and, just months ago, a hysterectomy. Before the year is out, she's expected to go under the knife a few more times, both for routine procedures and a likely revision to one of her hip replacements.

As anyone familiar with the American healthcare system might imagine, she has accrued debilitating debt along the way. Some of it stems from copays, deductibles and procedures insurance doesn't cover. But there are smaller, hidden costs of being sick, too, that can be just as daunting as they add up: medications, equipment, travel and dietary supplements, to name a few. As if that wasn't enough, Keilani was laid off from her job in 2022 as she was recovering from brain surgery. She has been unable to work since.

Through it all, Keilani has maintained her ineffable spirit and effervescent charm. She's bravely continued her work as an artist and as an advocate for disability rights. But even heroes sometimes need help. So we're throwing her benefit that's reflective of her passions as an artist, activist and devoted friend, called Limelight.