

NARRATOR:

The Disability & Philanthropy Forum presents Lillie Lainoff, author of *One For All*.

LILLIE LAINOFF:

I didn't identify as disabled until I was an undergraduate in college, partially because of stigma, partially because of the fact that I'd bought into the narrative that society tells us, that if you can hide your disability you should. And that it's something to be ashamed of. I was diagnosed with POTS syndrome when I was 14 years old. I had just started high school, a brand-new high school. I was learning to navigate high school while I was learning to navigate this body that was not really doing what it was supposed to be doing. At the same time I was having to explain to so many students, other students and teachers, what my condition was, when I didn't really even understand it completely myself at that point.

There were a lot of times when I struggled to get the accommodations that I needed, teachers would refuse to give me the accommodations that were granted to me by my IEP. I remember poignantly one memory in high school of being on the elevator and a security guard pulling me off the elevator, even though I had an elevator pass, because she said that I didn't look like I belonged there. And so that informed both how I talked about my chronic illness and also how I felt about it. Before I went off to college, I decided that I was not going to tell anyone that I was disabled.

Because in my mind telling people, these new people at college that I was disabled would make it harder for me to make friends, would make it harder for me to find anybody who would want to date me because we're taught that disabled people, specifically disabled women are not desirable. I thought that people would think I was weak. Obviously hiding a chronic illness and disability is pretty difficult, especially when those symptoms manifest physically. So that lasted for all of about a week. And I realized because I was surrounded by people who supported me and friends who supported me, that I felt comfortable in talking about my disability for the first time.

I still wasn't calling it a disability yet though. And that didn't happen until I was lucky enough to have an op-ed published by the Washington post in which I talked about being a chronically ill teenager. And at that point I had always wanted to be an author. I had always wanted to be a writer, but I very quickly realized after the outpouring of love and support, but also messages from people who had POTS saying, I didn't know anybody else who had this, thank you for talking about this in a national newspaper, in this large scale. I realized that it didn't just have to be about my words being in print, that they could mean something more.

That I had the opportunity to use my platform, to use the thing that I love, which is writing, to provide representation for the teenager that I was and for teenagers today.

NARRATOR:

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