

## Profile: Ilana Jacqueline



By Trudie Mitschang

nosed immune deficiency meant constantly battling infections that never resolved with the same treatment that my peers received. It meant always feeling run down. Despite all the red flags, plentiful hospital admissions and multiple specialists, no one ever connected the dots. When I was 19, I finally encountered an infectious disease doctor who looked over my history and started running the right tests. Having a diagnosis of primary immune deficiency disease explained so much, but getting on the right treatment was another journey. It would be 10 years after my original diagnosis before I had an immunologist who knew how to help me manage my disease. At 30 years old, finally on consistent weekly subcutaneous immune globulin therapy, I experienced my first full year without an infection.

**Trudie:** For those who don't know, what is medical gaslighting?

**Ilana:** Medical gaslighting is the act of healthcare providers dismissing or ignoring patients' concerns or complaints and leaving them without a clear treatment plan or diagnosis, often stating that the patients have an unspecified mental illness or are exhibiting an unnecessary amount of caution.

**Trudie:** How common is this experience among patients in the chronic illness community?

**Ilana:** It's actually pretty common for patients with immune deficiencies to experience gaslighting throughout their diagnostic odyssey. I've enjoyed a 15-year career of interviewing patients with rare diseases and interviewing women with chronic illnesses in particular, and I've yet to come across even one patient who hasn't had some experience with being

medically gaslit either on their way to becoming diagnosed or after diagnosis, and being questioned by other hospital staff or specialists about whether they were "really informed" about their diagnosis.

**Trudie:** What inspired you to write your book?

**Ilana:** You would think that after cementing a diagnosis, becoming an adult with a career in patient advocacy, and working with patients and physicians for so many years, that a doctor would not be able to gaslight me. But the reality is that to this day, I still encounter doctors who make the attempt. I knew, at some point, how to handle gaslighting in the exam room by having tried different tactics, but I wanted to know more. Why was I being gaslit? Who was teaching doctors to interact with patients this way? Was it just because I had a rare disease and a complex medical history, or did this happen to newly diagnosed patients with more common illnesses? I had a lot of questions and, for a few weeks, I considered turning that research into an editorial. But each time I was able to figure out the answer to one question, 10 more came in its place. I knew that the answers I really wanted were going to take time, effort and collaboration. To give the subject the in-depth investigation it deserved, I realized this was going to be a book.

**Trudie:** What has your research uncovered about the root cause of bias?

**Ilana:** There are so many factors that can cause a doctor to have a bias against you: It can be your age, your gender, your race, your profession, even just the color of your hair. And you can't always perfectly balance that power imbalance. But there

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**Trudie:** Can you briefly share your diagnosis story with our readers?

**Ilana:** Growing up with an undiag-

are a few tricks like providing a witness, bringing in evidence of your condition such as symptom journals, and navigating the conversation calmly and confidently that can help you out in situations in which you can't access better care.

**Trudie:** Can you share a particular low point in your experiences with gaslighting?

**Ilana:** In one situation, I couldn't change doctors because no other providers in my area were accepting new patients. The provider I was seeing for pain management was openly hostile with me almost as soon as I walked into the room. He sneered at my explanations of pain and shamed me for not better managing my condition. He would get angry when I told him the treatments weren't working, that I was still having breakthrough pain. There was a clear power imbalance in the relationship, and I was scared to even bring up additional issues for fear he would lash out and I would be kicked out of the only open practice in my town.

**Trudie:** What "lessons learned" help you stand up for yourself during medical appointments today?

**Ilana:** All of my mistakes were really helpful in educating me on the best way to combat gaslighting. I like to think that my real research into this topic went back years. I sat down and analyzed all of my major encounters: What had I said? What had the doctor said? What evidence had I provided? What was I asking for help with? I started to record conversations in the exam room and listen to them — sometimes alone, and sometimes with my family to get their perspective on what went wrong. Some big takeaways were that I had to stick to the facts. It's hard to gaslight evidence: charts, symptom logs, blood tests. I also had to know when to end an appointment. Some doctors were

not going to help me, and there really wasn't anything I could do or say to convince them to help me. Learning to leave a room that doesn't serve you was a radical realization.

**Trudie:** What support should readers seek if they are experiencing gaslighting?


**Ilana:** Support is important, and if readers have experienced medical gaslighting that leads to medical trauma, they should seek out a therapist with expertise in that area. However, more than just supporting or treating the aftermath of medical gaslighting, patients need to learn how to strategically fight back in a way that gets them the answers they need. This is the situation-by-situation playbook that covers responses to common phrases used when gaslighting a patient, how to understand when gaslighting has been notated in an electronic medical record, and how to refute it before it poisons the well with future members of your care team. There is a way to fight back that doesn't involve extreme confrontation, but instead gets doctors to admit their line of thinking isn't a reasonable response to the situation you're experiencing.

**Trudie:** Should patients hire a personal advocate?

**Ilana:** Shockingly to many who know me, I normally don't ever advise patients to do this. If the expectation of the patient looking to hire an advocate is that someone will become intimately familiar with your case, your medical history, your medications, your goals, your priorities, your allergies and the relationships already existing with your current providers — and then join you in the exam room for future appointments — it's going to cost you a fortune. Just to become acclimated to your case might require a minimum of six hours for an advocate who, if paid hourly, usually charges from \$50 to \$200 an hour. You

will still have to be equally updated on your own case, present for all future appointments and, in the end, make the right decision for you on treatment.

**Trudie:** Are there other types of advocates that might be more affordable?

**Ilana:** Yes. There are still many opportunities to access different types of patient advocates who don't work on individual cases. For instance, your insurance company most likely has programs that have virtual advocates available to you at no cost. These advocates can call your doctor's office daily to work out issues with medication coverage, prior authorization and even appointment scheduling. Social workers can act as both therapists and advocates to your other healthcare providers, making calls on your behalf that might otherwise be ignored. Keep in mind that an advocate who works for your hospital may help you access different resources, set up appointments with outside providers, or even organize rides to and from appointments. But if you have an issue regarding the quality of your care, a hospital patient advocate is not going to advocate for you. They are paid by the hospital, and their job is to de-escalate conflicts and reduce the number of lawsuits brought to that hospital. If you suspect medical negligence or malpractice has taken place, you don't need an advocate. You need a lawyer. 

*Editor's note: Ilana's book *Medical Gaslighting: How to Get the Care You Deserve in a System That Makes You Fight for Your Life* can be purchased on Amazon.com and wherever books are sold.*



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