

## Profile: Mindy Bedrossian



By Trudie Mitschang

the start of a 20-plus year journey to the real diagnosis, finally in my 50s, of CIDP. It took that long to get it right.

**Trudie:** Tell us about your immune globulin (IG) treatment plan.

**Mindy:** I started on monthly intravenous IG (IVIG) once I was correctly diagnosed and after a whole lot of tests. I was not one of those people who have a quick response and there's an astonishing improvement overnight, but over the next four months I did see improvement. I also got aseptic meningitis from the IVIG being administered too quickly. Once it was slowed down dramatically, the migraines I initially suffered were not as debilitating. I was a high school teacher at the time, and it was not unusual to see me walking the halls of the high school wearing sunglasses the days of my infusions.

**Trudie:** When and why did you switch to subcutaneous IG (SCIG)?

**Mindy:** I was on my third port over 15 years when COVID came along. I always had my infusions at home, but at age 65, Medicare insisted I go to an infusion center. I know that in some areas Medicare approves home infusions, but not where I live. I immediately switched to SCIG and have never looked back. My last port was surgically removed about a year after I switched to SCIG. And no more migraines!

**Trudie:** What was the inspiration for your three-week globe-trotting trip?

**Mindy:** My younger son was getting married to a young lady from India this past December, and of course, I wasn't going to miss an Indian wedding! My older son is married to a Thai woman (we're a very international family!)

and I would be traveling straight from Mumbai to Chiang Mai in Thailand where they live. I literally would have to circumnavigate the world to get back home to Ohio where I live.

**Trudie:** How did you prepare given your medical condition and physical limitations?

**Mindy:** I honestly spent months working out all the details of this trip. I would be traveling alone the entire time, and this would not be easy. Like many autoimmune disease patients, I have had a virtual cascade of common and strange autoimmune diseases descend on me. From diabetes to arthritis to rare things such as inflammation on the inside of my eyes, to sores covering my tongue, to an outbreak of plaque psoriasis appearing for the first time at age 70. All these things required a lot of medicine for me to carry, in addition to carrying three weeks of SCIG doses plus supplies. Also, because of the CIDP, I walk with a cane. I am slow, easily fatigued and have very poor balance. There was a lot to consider!

**Trudie:** Tell us about the planning process.

**Mindy:** I created all sorts of lists, trying to anticipate every possible scenario. First, I registered with all the airlines, including foreign ones, to make sure I would get wheelchairs to and from every plane. My daughter-in-law in Thailand assisted in getting some of the foreign airlines to agree to provide a wheelchair. Just registering with U.S. airlines does not get you help overseas. Each one of those airlines requires a separate contact, either by phone or email. This was incredibly important because I didn't want to have to wait on long lines

**AT AGE 70**, Mindy Bedrossian lives with multiple chronic illnesses, including chronic inflammatory demyelinating polyneuropathy (CIDP). But that didn't stop the Ohio resident from catching eleven flights, enduring hours sitting in multiple airports and essentially circumventing the globe for a once-in-a-lifetime trip to India and Thailand this past December. Here, she shares highlights from her fearless journey and tips for others who want to push past boundaries and see the world on their own terms.

**Trudie:** When were you diagnosed with a chronic immune disease, and what is your diagnosis?

**Mindy:** I had my first symptoms when I was 30 years old and pregnant with twins. I was on complete bed rest, and since I loved quilting, I kept myself busy by creating two baby quilts for myself. But I kept dropping the needle and my hands kept getting numb and tingly. The doctor said it was carpal tunnel. "In both hands?" I asked. I knew immediately that was the wrong diagnosis. That was

in which I would have to stand, which I just can't do. Second, I looked at my medications, especially the SCIG. If you look online, you will see these little suitcases for medical items, but have you tried to carry these with your other bags? They are heavy, awkward and ridiculous to carry if you've got a large bag with all your other items, plus a big suitcase to haul. My hands are weak, so there was no way I could manage that. Yet I knew I needed the IG medication on my person at all times.

**Trudie:** What airline restrictions did you navigate?

**Mindy:** Many flights now forcibly take your carry-on suitcase and insist it goes in the luggage compartment of the plane anyway. That cannot be permitted with IG medication. I bought a special backpack that's theft-proof (lined with cut-proof mesh inside), and I put the IG medication and all the supplies necessary inside (including the vials, pump, syringes, tubing, gloves, etc.). Inside, I had a letter from my physician verifying it was a medical necessity. Carrying everything in a backpack made it easier to walk with a cane.

**Trudie:** How did you find space in hotel rooms to do your infusions?

**Mindy:** This was actually a bit tricky. I would spread a sterile drape on the bed, lay out my materials, and basically do it that way. If the room had a chair and desk, I did it there instead. I kept a clean towel and a soapy washcloth with me as well so I could clean my hands as needed. There were a lot of different rooms I stayed in, so I had to adjust to each one. I did not have a single problem doing it this way. I just needed to make sure I was in a comfortable position to get it done.

**Trudie:** What other unique challenges did you face, and how did you overcome them?



*To carry all of her medications, including her SCIG supplies, as she navigated eleven different flights to India for her son's wedding, Mindy purchased a theft-proof backpack she could wear on her back while also managing her other luggage.*

**Mindy:** Most people are unaware of the fact that the IG medication is stable at room temperature for up to a month. I didn't have to worry about keeping it refrigerated for this three-week trip. However, something to be aware of is that some hotels in Asia are set up so the electricity in the room only turns on when a card key is inserted into a slot. That means that even if there is a fridge in the room, it will go off once you leave. Since it can easily hit 100° F or more outside, these rooms can get very hot. Always request a second card key so you can keep the power on when you're not there. Make sure you explain to the staff that the AC/fridge must remain on at all times so the medication doesn't get too hot.

**Trudie:** Were there any issues with airport security?

**Mindy:** I only needed to show my letter when there were questions about the supplies. I think that it was quite obvious it was some sort of medication, and I was in a wheelchair with a cane as well.


**Trudie:** What did you learn about yourself during this adventure?

**Mindy:** My family tried to convince me not to do this trip. Nobody thought I could manage it! Eleven flights, hours sitting in airports waiting for the next plane, wondering if I could make it to the next ticket counter. It was quite the adventure, and I did it!

**Trudie:** What advice do you have for others who want to travel, despite their physical limitations and diagnosis?

**Mindy:** Plan for every single possible eventuality — from cancelled flights, to lost luggage, to getting sick on the journey. Keep your medications with you at all times. Go slow, leave long layovers so you don't have to rush or worry about delays interfering with the next flight. Since I was traveling around the world in December during COVID and flu season, I bought expensive medical travelers' insurance that guaranteed a flight home for medical care. Thanks to my mask, the worst I caught was a mere cold.

**Trudie:** Were there any specific setbacks you had to navigate?

**Mindy:** Since I had to carry my IG supplies along with insulin and other medications, I only carried some high protein snacks and a Kindle with me. Some of my flights left me overnight in airports where all the food kiosks were closed. One airport was so crowded that people were sitting on the floor with piles of luggage around them. I couldn't go to the bathroom the entire night because I would lose my seat if I did. But looking back, I wouldn't have missed this trip for the world! 



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