

Adventures in Accessibility: Exploring the World with Rett Syndrome

To be perfectly honest, more than once this past spring, I found myself asking: “Is this madness? Should we even dare? Are we even *allowed* to have this life?”

We were facing a packed itinerary for the summer—Germany, Poland, Italy, and India—bringing equal parts trepidation and excitement. What started as travel surrounding a study abroad program I developed for the University of Georgia, entitled *Language, Power, and Globalization*, set in Munich and Berlin, quickly expanded. Invitations for academic talks on my research with my daughter, Kalika, who is eight years old and has Rett syndrome, arrived from Poland and Italy. And since we would be already halfway there, we added a visit to my hometown of New Delhi, India.

It wasn't a decision we took lightly. Months of preparation went into this—planning medication schedules, packing for different climates, coordinating medical equipment, and what seemed to be a million other things. And of course, making sure our cats would be cared for back home.

The summer heat wouldn't be kind to us, either in Europe or in India, but we embraced the world and made some unforgettable memories.

Kalika, our little adventurer, thrived. She savored pretzels in a Munich biergarten, indulged in delicious pasta in Rome, and enjoyed pierogis in Warsaw. Museums and history came alive for her as she explored the Jewish Museum in Berlin, strolled through Warsaw's Old Town, and admired old artifacts in the Polish National Museum. In Rome, Kalika marveled at the art in the Sistine Chapel and loved the intricately carved statues of the National Roman Museum. Castel Gandolfo offered us a peaceful, breezy beach day on a volcanic crater lake.

India, however, was a different experience. We stayed indoors, sweltering in suburban New Delhi's intense heat, waiting for the monsoons to arrive at the tail end of our trip. Kalika loved hanging out with her beloved grandparents and eating delicious Indian food prepared by her Hindi-speaking nanny—an interesting language immersion for a child who communicates, using a speech device, in Bangla and English.

Traveling with a child with Rett syndrome presents challenges most people can't imagine. We rely on a well-worn travel checklist that we started a few years ago. Kalika has now been to 12 countries, some of them (like India, France, and Italy) multiple times. Our travel list evolves with every trip, depending on Kalika's symptoms. Still, things slip through the cracks—this time, we forgot her travel pillow. And, yes, we left behind the wheelchair mount for her speech device on the last night of our summer travels, a mistake that cost us \$1,500. We've had to change plans before when her health worsened, or new symptoms emerged. The only predictable part of traveling with Rett syndrome is its unpredictability.

This summer brought highs and lows. While security checks in Munich, Warsaw, and Rome were smooth, London Heathrow was a different story. They inspected everything, from our G-tube feeds to Kalika's temperature-controlled meds, showing no compassion for our tight travel schedule. In Munich, a grumpy taxi driver wasn't thrilled about fitting her wheelchair in. But on the bright side, Kalika discovered new foods—Tuc crackers in

Berlin, kachapuri at a Georgian restaurant in Warsaw, and yummy shaag posto (sautéed spinach in poppy seed paste) in India.

There were moments when it felt overwhelming. It's hard for Kalika to be without routine. It was tough to push a wheelchair over cobblestones and deal with the stares in parks and restaurants. We missed so many of her occupational, physical, and feeding therapy sessions. We had to explain Rett syndrome and Kalika's communication method over and over again. Out of order elevators at metro stations threw off our plans multiple times. A leaking seizure medicine bottle meant getting a new prescription for a strictly controlled drug in India. And after a year without seizures, Kalika had "head drops" again at a museum restaurant in Warsaw. Seeing her suffer due to travel brought a knot of guilt to my stomach.

But then I remembered how many times she tells us on her TD Pilot, her eye-tracking AAC device: "I love to travel." And she really does. Kalika is curious, adaptable, and open to the world. How could we rob her of that joy?

As an academic, I'm always planning at least a year ahead. But as a Rett mom, I feel guilty about planning for the next day. I still wrestle with those questions: "Is this madness? Should we even dare? Are we even supposed to have this life?" But then I remind myself that after her diagnosis, we promised her the best life possible—and this is it. She is supposed to have the world, and we will do everything in our power to bring it to her.

General tips for traveling with a child with Rett syndrome

- **Create and update a travel checklist:** Keep a detailed checklist in a Google Doc, and update it regularly based on your destination and your child's specific needs. Double-check this list before departure.
- **Pack essential medical supplies:** Bring all necessary prescriptions, medical letters from specialists, and medical equipment. Don't forget items like syringes, G Tube supplies, and any special medications your child needs.
- **Manage medications for jet lag:** Consult with your neurologist to adjust your child's medication schedule, especially for seizure meds, based on time zone changes.
- **Carry backup food options:** If your child is G Tube-fed, bring portable food preparation tools like a BlendJet and ensure you have backup snacks.
- **Track important items:** Set reminders on your phone to check key items like wheelchair mounts and medical devices, especially during transitions like boarding and disembarking. Spare chargers for all devices are essential.
- **Arrange disability assistance early:** Confirm special assistance requests with airlines and transportation services well in advance to avoid complications.
- **Research accessible transportation:** Plan ahead by checking which metro stations and public transport routes are wheelchair accessible at your destination.
- **Prepare for all weather:** Pack for different weather conditions, including cooling towels, travel pillows, and other comfort items.
- **Pre-load entertainment:** Load your child's favorite shows or games onto an iPad to keep them engaged during long waits.

- **Use translation apps:** Google Translate can help with navigating medical or dietary needs in countries where you don't speak the language.

Packing List (modeled on ours)

Documentation

- Passports
- Visas (if applicable) and printouts of those kept in a separate carryon
- Flight tickets and boarding passes
- Medical letters (for medications, G Tube, etc.)
- COVID-19 masks and health documentation (if required)

Electronics

- Speech device and charger
- iPad, headphones, and charging cords

Medical Needs

- **Medications:**
 - Pills
 - Liquids
 - Cold-stored liquids
 - Seizure spray
 - Supplements
- **Medical Supplies:**
 - Syringes for medication administration
 - Extra bottle caps (if applicable)
 - Mickey button replacements for G Tube (if applicable)
 - Bolus feeding attachments (if applicable)
 - Nose Frida and thermometer
 - Oral Rehydration Salts for dehydration prevention
 - Ice packs (frozen) for medication transport
 - Children's Acetaminophen and Ibuprofen (for fever/pain)
- **Backup Medical Information:**
 - Hard copies of prescriptions, doctor's notes, and emergency medication instructions.

Clothing and Personal Care

- **For Your Child:**
 - Diapers, wipes, masks, and necessary clothing
 - Comfortable, weather-appropriate clothes for varying climates