



*Tina's*

# BIG TRIP



★ THE  
★ INSPIRED  
★ BY  
★ SERIES

A rare disease story about  
going the extra mile



Tina's Big Trip

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**This book is inspired by Gianluca, Valentina, and Sofia.**

*"To my daughter, Valentina, who lives with a rare disease and teaches me every day what it means to love without conditions and how to forgive life's challenges. Traveling through Italy with you showed me the beauty of embracing the unexpected: how to slow down, how to listen, and how to celebrate every small victory. Your resilience and laughter are my greatest teachers. As a father and a researcher for rare diseases, I carry your lessons into my work and my life. Thank you for the privilege of this journey we share."*

**– Gianluca, Caregiver Parent**



## 1. Making the Lists

In Victoria and Tina’s family, getting ready for a trip means more than packing clothes and snacks. Tina has a rare disease, so traveling always takes extra—extra medicine, extra planning, and extra patience. But Papà said that was just part of their rhythm. “Going the extra mile,” he liked to say, “is part of the journey.”

Victoria didn’t mind the extra planning. But she did mind the fridge.

It had never looked so messy! Not even before the first day of school, when it had been covered in supply lists. Not even after art camp, when she’d taped up all her masterpieces.

Now it was covered in lists again—but not fun ones like BEST MOVIES EVER. Not even boring ones like AFTER-SCHOOL CHORES. These lists were all about a trip to Italy.

Papà had printed out lists for all of them, and Victoria double-checked hers. One said SUITCASE—and that one included everything from barrettes to her favorite green shoes. The other said CARRY-ON, and she had decorated it with a smiley face sticker because it was for the really important stuff, like her favorite sticker book, her colored pencils, and her stuffed turtle.

Tina also had a suitcase and carry-on list, but she had extra ones too. These were mostly reminders for Papà: PACK SAFETY BED, CHARGE BATTERY, BRING THERAPY COOLER. There was even a card with Tina’s name on it, so the transportation agents would know that she needed Papà to help her go through security screening.

Papà stood back, scanning the fridge for a free space. He didn’t seem bothered by the clutter. In fact, he put up a new list!

“This,” he said, tapping the corner of the paper, “is what will make the journey smoother.”

“It’s a travel checklist,” Papà explained. “Our rare disease advocacy group has a lot of resources we can download, including some for families who travel. This one helps me remember to bring everything that Tina needs, like her wheelchair and her medication, but I also add things to it. I think we all know what Tina wants to take on this trip. She needs snacks, her tablet, and a few good jokes. Right, Tina?”

“And Pete!” Tina piped up from her cozy spot on the couch.

Victoria giggled and looked back at the fridge. But her smile faded when she saw that someone had drawn a thick, black line through one item on Tina's list: Pete.

“I want you to have what you need,” Papà said, “but I have to draw the line at taking the neighbor's cat.”

“He wants to come!” Tina said.

“And why wouldn't he?” Papà replied cheerfully. “Napoli! My childhood home. The city of the sun! But can you really imagine taking Pete on a plane?”

It wasn't hard to imagine at all, Victoria thought. Pete liked to sit on Tina's lap. He wasn't afraid of her wheelchair either. He was tall and dignified as they rolled down the hallway, all orange except for his white socks and nose.

“It's impossible, sweetheart,” Papà said.

Tina looked away. “Not impossible,” she murmured. “Just not allowed.”

Victoria shuffled the magnets around. Papà's notes were important, but they were also pretty dull. She pulled out the special list she and Tina had made and stuck it to the fridge with a magnet.

Their list had only three things:



“Now this one is fun!” Victoria said.

By the door, Papà was lining up the luggage. His dark blue suitcase looked plain next to Victoria's princess bag and Tina's rainbow-colored backpack.

He came to stand behind her and leaned his chin on the top of Victoria's head while he read the note. Then he gave an impressed whistle. “I can't beat that. Yours is much more exciting than mine. But your list is for the fun we'll have when we get there. Mine is to make sure we arrive safe and happy.”

Going to Italy sounded simple, Victoria thought. You go to the airport. You get on a plane. Then there's one amazing second when the wheels lift off the ground and suddenly, you're flying.

But for their family, it wasn't simple. Traveling was hard for Tina. There were too many bags, too many rules, and too much noise. She didn't get to choose when to move around or when to sit down. Even her tablet—her favorite thing—had to disappear at times during the flight. Victoria wished she could make it easier on her sister.

She glanced back at Papà's list. This time, she noticed things she hadn't before. He had written down: SNACKS, WORD GAMES, JOKE BOOKS. At first, they looked like ordinary travel items, but Victoria realized they weren't really for him at all. They were things he would bring to help Tina feel okay during the times when she couldn't use her tablet.

Victoria chewed the cap of her pen and concentrated. There had to be something else. Something fun, but quiet. Something that didn't need a screen.



Then she remembered the little bag in the bathroom drawer.

She dashed off and came back with lip balm, sunscreen, and the glittery face masks Nanny Olivia had given them. If they had to wait a long time, this could be their secret weapon. A quiet, screen-free way to pass the time.

She drew a new box on the packing list and wrote: AIRPLANE BEAUTY SPA.

Papà took one look over her shoulder, then walked straight over to where her sticker book was sitting on the table. He grabbed it and peeled off an enormous yellow star and handed it to her.

“That’s for having an extra good idea,” he said. “Airplane beauty spa? You know your sister so well. She’ll love that.”

“Can I put it on the blue suitcase?” Victoria asked.

Papà nodded. “Yes. In fact, ...I think we should decorate my suitcase with a sticker every time someone goes the extra mile.”

Victoria tilted her head. “What does that mean?”

Papà smiled and considered the question. “Going the extra mile just means going further than you have to. Going the extra step. Being extra helpful or extra brave. Anyone who does something hard or kind, even if it’s small, is going the extra distance.”

Victoria liked that. She ran over and slapped the star against the front of the suitcase. It looked a little lonely by itself, but also a little proud.

“One down,” she said, “and room for lots more.”





## 2. Managing the Airport

Tina hadn't expected the airport to be so loud. There were announcements crackling overhead, suitcases clattering across the floor, and voices bouncing off every shiny surface. All the sounds seemed to press in at once.

"It's busy in here," Papà said, "but I thought this flight would be just right. You'll be tired enough to nap once we're in the air."

Tina pulled her hoodie up, slid on her headset, and gripped her tablet with both hands. The plan had been to watch a video and zone out, but the sounds still leaked in around the edges.

A friend from their advocacy group had helped Papà learn how to organize something called airport assistance. The lady who met them to help them through the airport was cheerful and kind. She led them through a special line at security, and one of the staff even carried the bins so Papà could focus on Tina's wheelchair and medical travel cooler.

Still, it was a lot, even with the extra help of airport staff and strangers.

When it was her turn to go through security, Tina had to hand over her hoodie and her tablet for just a minute. But she got them back as soon as they were through the checkpoint.

She wanted to go to Italy. She couldn't wait to be there! But it felt like everything so far was just waiting and noise.

In the tunnel to the plane, Papà pushed her chair while balancing the carry-ons over one arm. The airport assistant folded the wheelchair at the door, and a flight attendant stepped in to help: stowing the bags and helping set up Tina's special seat. Tina liked having her chair close by, but she could walk too, just not quickly. Holding onto the seats as she went, she took her time. Papà stayed close, steadying her as she climbed in, and Victoria helped buckle the seat belt across her lap.

Once they were settled, other people started filling up the plane. They stood in the aisles and put bags into the overhead compartments. The lights were so bright, and the air smelled strange—clean and dry, like plastic.

She didn't want to be here.

The tablet helped. On the screen, everything stayed the same. The voices were the ones she chose. The colors and sounds came exactly when she expected them. It made the rest of the plane feel farther away. Safer.

Without it, everything felt too close, too bright, too loud. Like anything could happen.

The flight attendant crouched down to eye level. “Sweetheart, we’ll need all devices powered down for takeoff. I’ll keep an eye on it for you, and we’ll hand it right back once we’re in the air, okay?”

Papà leaned in. “Just like we practiced. You can have it back soon.”

Her fingers tightened around the tablet.

She felt like she might cry, but she pressed her lips shut tight and breathed slowly in and out through her nose. The flight attendant was still waiting. Papà was watching. Victoria kept glancing at her, wide-eyed. And all Tina could think was how much she wished they would stop.

Papà’s hand was gentle but firm as he slid the tablet away. Tina shut her eyes and imagined Pete curled up on her lap. That helped a little. She didn’t open her eyes until the flight attendant moved away.

Then something cool and a little slippery pressed into her palm.

She looked down.

Victoria had pulled out the beauty spa kit. “Look what I have,” she whispered. “Want to do face masks?”

Victoria held one up. The silver packaging glittered in the overhead light.

Tina stared at it. She loved face masks.

Slowly, she gave a small nod.

Victoria passed her the other mask. They unfolded them carefully, then pressed them onto their faces. The mask was cool against Tina’s skin and smelled faintly like strawberries. She pictured herself at a spa, like the one Papà had taken her to on her birthday.

Then she glanced at Victoria. The mask left big holes around her eyes and mouth. She looked like a wide-eyed ghost.

Tina giggled.

“Ready for takeoff,” Victoria said, just loud enough for her to hear. “After this, we have a lip scrub!”

As the plane began to move, Papà leaned across the aisle and handed Tina a sticker shaped like a plane.



“For extra patience,” he said.

Tina smoothed the edges with her thumb.

She looked toward Victoria, who reached for the suitcase, then stopped herself.

“It’s with our other luggage,” Victoria said. “We’ll put it on when we get to Italy. That’ll be extra EXTRA patience.”

Tina gave her a sideways look. Not quite a smile. But almost.

The plane thundered down the runway. Her stomach flipped as the wheels lifted off the ground. She leaned back in her seat, the mask cool on her skin.

They were really doing it.

They were going to Italy!

Across the aisle, Papà let out a long breath and rubbed his hands over his eyes. His shoulders sagged, and for a moment, he looked very tired.

But then he straightened and smiled—the kind of smile that said this part was worth it.



### 3. Moving to a New Plan

Victoria had never been to Italy before, and Tina hadn't been since she was a baby. They were used to their own city with its modern buildings and yellow taxis. But Naples was different. It was like a painting come to life. The balconies were draped with laundry, string lights zigzagged overhead, and the air buzzed with church bells, clinking cutlery, and voices calling from open windows.

The sun felt brighter than it did at home. Sharper, somehow, like it was turned up a notch. Victoria pressed a cold bottle of water to her forehead as they rolled Tina toward the station at the base of the hill.

"We're going to ride a hill train," Papà said, eyes bright. "It climbs all the way up to the top of the city like a mountain tram."

"I used to come up here after school with my best friend, Antonio," Papà said. "Those afternoons are some of my best memories of this city."

Victoria had heard about Antonio many times before. Still, she glanced around, trying to picture her Papà as a boy walking along the stone streets. She tried to catch Tina's eyes, but they were already half-hidden, her "Don't talk to me" look. Victoria knew that one.

"You'll see everything from up there," Papà said, sounding excited. "The rooftops, the bay, and the volcano. Oh, wait until you see it."

"Vesuvius," Victoria said, like she was tasting the word.

"Exactly," Papà said. "It's a great sight when it's not erupting."

Victoria laughed. Tina didn't.

They reached the platform just as the next train arrived with a squeal and a shudder. The car was older than Victoria expected, with wooden benches and signs in Italian that Papà read aloud. But there were also stairs—two long stone ones—and no ramp.

"I can carry her partway," Papà said quickly. "Victoria, can you hold the back wheels?"

Victoria nodded, but her stomach fluttered. Papà had the heavy end, but what if she bumped the wheels or pinched Tina's arm?

But then something happened.

A couple who'd been waiting nearby stepped forward. The man pointed to the chair and said something in Italian.

"*Posso aiutare?*" he asked, already taking hold of the front bar.

Papà looked surprised at the man's offer to help, but then he smiled. "*Grazie mille. Gentilissimo.*"

Victoria didn't speak Italian, but she knew that meant thank you.

Between them, they lifted the chair smoothly up the stairs and onto the train. Tina looked startled, then settled back into her seat without a word.

Victoria's heart felt suddenly warm. Most of the time, it was Papà who made everything work. But sometimes, a stranger stepped in and made it easier. She touched her sticker book and wondered if she could offer one, but by the time she found her courage, the couple were hurrying on their way.

At the next stop, things fell apart again.

There were more stairs, even steeper this time. No elevator. No ramp.

Tina didn't move.

"We'll carry you again," Papà said gently.

"No," she said. Her voice was quiet, but firm.

All morning the wheels of Tina's chair had jolted over cobblestones as they went from streets to museums to shops. Victoria watched her get quieter and heavier, as if she were being pulled down into her seat. By now Tina looked hot, dusty, and tired, and Victoria knew the day didn't feel like hers anymore.

Victoria wanted to say they were almost there, but stopped. Tina's hands were clenched into fists.

"I don't want to!"

Tina's voice echoed in the little station. Her cheeks were red. She wasn't just mad. She looked stuck.

Victoria froze.

People were watching. Papà rubbed the back of his neck and looked thoughtful. For a moment, everything was still.

He looked at Tina, then at the stairs, then back again.

"I should have checked this stop," he said quietly. "I tried to plan everything, but I missed this one."

He knelt beside Tina's chair. "I'm sorry, love. It's not fair to keep asking you to push through."

Then he let out a long breath.

"You know what?" he said. "Change of plan. I think we need a break. Who wants pizza?"

The pizzeria was hundreds of years old. It was tucked behind a red awning, just off a nearby square, with wobbly iron tables spilling into the street. The waiter nodded when Papà ordered "*Una pizza Margherita con mozzarella di bufala.*" The pizza came fresh from a stone oven, with tomatoes like rubies,



snowy mozzarella, and whole green basil leaves, and Papà carried it from the restaurant to the iron tables outside. The door to the restaurant had one big step, so they ate outdoors instead.

Tina didn't say anything, but she took a slice right away. There was almost nothing she liked more than pizza.

"It's red, white, and green, like the Italian flag!" Papà said.

Tina still wasn't talking, but she was eating.

Victoria tore off a piece of her slice and looked out across the buildings. To her surprise, if she leaned just a little, the volcano was visible from here too—a soft triangle against a pink and blue sky.

"Wow," she said. "There it is!"

Papà followed her gaze and smiled. He gestured toward the top of the hill.

"Antonio and I used to sit up there after school, talking about everything: traveling, the future, even the meaning of life. We were philosophical kids, I guess. I always think of him when I come back."

Victoria chewed thoughtfully. “Do you still miss him?”

Papà nodded. He looked at the table, the pizza, the view.

“I sure do. Those memories will always stay with me. But it means a lot to me to be able to make new memories with my girls.”

Just then, Tina sat up straighter and pointed dramatically.

“Pete!”

Across the square, a small orange cat was weaving between café chairs, tail high, white socks flashing with every step.

It paused, turned toward them with moonlike eyes, and blinked.

Victoria watched Tina’s face shift, her whole expression softening into something calm and amazed.

“I told you he wanted to come,” Tina said, her mouth twitching at the corners.

Papà smiled. “Did you pack him just in case?”

Victoria leaned closer. “Should we get him his own slice?”

Tina laughed and popped a tomato into her mouth.

When they got back to Nonna and Nonno’s house, Victoria opened the side pocket of her backpack.

She peeled off a sticker shaped like a slice of pizza.

“This one’s for today,” she said. “For the pizza place, Papà changing the plans, and the people who helped.”

Tina nodded and pressed it onto the suitcase.

Papà smiled. “Sometimes strangers carry us the extra distance.”

The suitcase was starting to look more like a patchwork quilt, full of small victories.

And that pizza, she thought, was the most special slice in all of Naples.





#### 4. Making Memories

On their last day in Italy, after visiting cousins and wandering through museums and gardens, the air felt slower, like the city was trying to convince them to stay. The morning was soft and golden, and Papà said they had time for one last stop before heading to the airport.

“Just one more thing,” he said, locking eyes with Tina and Victoria. “Any guesses?”

“Gelato,” Victoria said immediately.

“Gelato,” Tina agreed again, with the air of someone stating a universal truth.

They found a small shop on a quiet corner, with old tiles on the floor and pastel colors in the case. Victoria chose *stracciatella*, which was white gelato dotted with delicate curls of dark chocolate. Tina picked *pistacchio*, which Papà said was the most sophisticated flavor. He ordered *nocciola*, a sweet hazelnut flavor, for himself—and declared, as always, that his was the best.

They sat on a low wall outside, legs swinging, sharing spoonfuls. Tina’s chair was already drawn up beside them, resting in the same patch of sun. A family walked by, chattering in Italian, and a boy on a scooter zoomed past, driving with one hand and eating a slice of focaccia with the other. The street smelled like espresso and sun-warmed stone.

Victoria leaned against Papà’s arm.

“I wish we didn’t have to go home.”

Papà took a slow bite of his gelato and looked out at the street. “Me too. But I’m glad we came. A trip like this takes a village—friends, strangers, and, most of all, family. I’m grateful for every hand that helped us get here.”

“We didn’t go to Capri,” Tina said.

“No,” Papà agreed. “I talked with other parents in our support group, and they recommended skipping it because there are too many stairs. I think I’ll let them know about our train adventure so we can give good advice to other people who come to Naples! I remembered the trains differently, so it’s a good reminder to double-check even when you think you know. And really,” he added, “a great trip doesn’t mean everything has to be perfect. It just means we find joy in the places where we end up.” He smiled. “We found our own special spot to see Vesuvius, and we’ve made great memories.”

Tina put down her empty cup and reached into the bag hanging from the back of her wheelchair.

“My turn,” she said.

She peeled off a new sticker—this one shaped like an ice-cream cone—and pressed it firmly onto the back of Papà’s hand.

“For more gelato,” she said, raising her eyebrows like she was making a very serious point.

Papà laughed. “More gelato? You know just how to use the rules to your advantage.” He scooped a spoonful from his own cup of *nocciola* and held it out to her. “Here, more gelato, as promised.”

Tina grinned and took the bite, clearly pleased with herself.

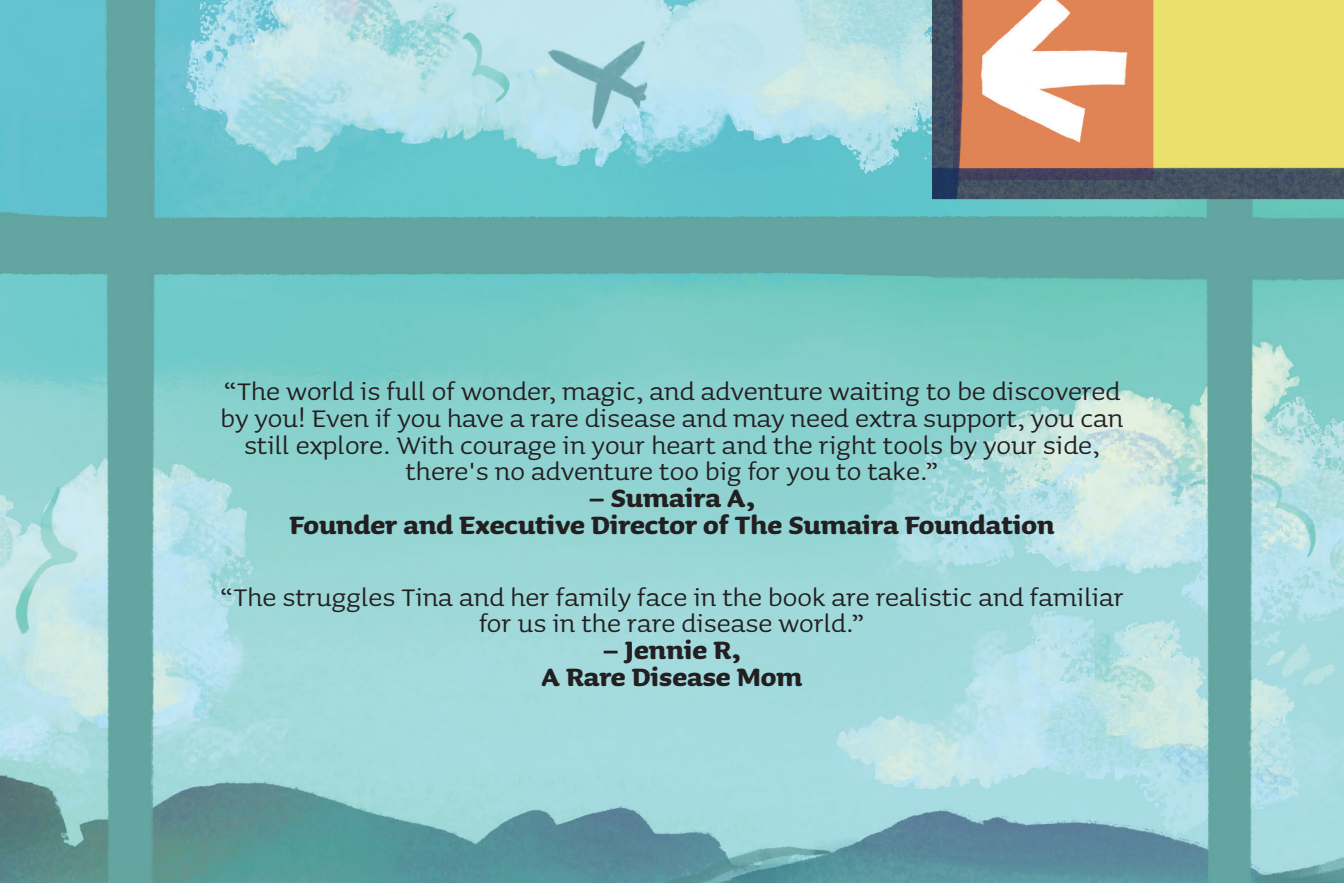
And for a little while longer, they stayed there, feeling sunny, sticky, and content. It wasn’t the biggest thing they’d done in Italy. But it might have been the best. It was a moment for the list of memories they kept in their hearts.

The best part of the trip was being together with you,” Papà said. Then he licked his spoon and chuckled ruefully, “Now, who’s ready to do this whole trip again, but backward?”

Tina let her head fall against the back of her chair. Victoria groaned.

But both of them were smiling.





“The world is full of wonder, magic, and adventure waiting to be discovered by you! Even if you have a rare disease and may need extra support, you can still explore. With courage in your heart and the right tools by your side, there's no adventure too big for you to take.”

– **Sumaira A,**  
**Founder and Executive Director of The Sumaira Foundation**

“The struggles Tina and her family face in the book are realistic and familiar for us in the rare disease world.”

– **Jennie R,**  
**A Rare Disease Mom**



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