

# The Ups And Downs Of Our World.

A Collection of Narratives.



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Written by

**Ms. Veeravalli Sarah Smily**

**Dr. Lalita Joshi**

**Mrs. Thungambika**

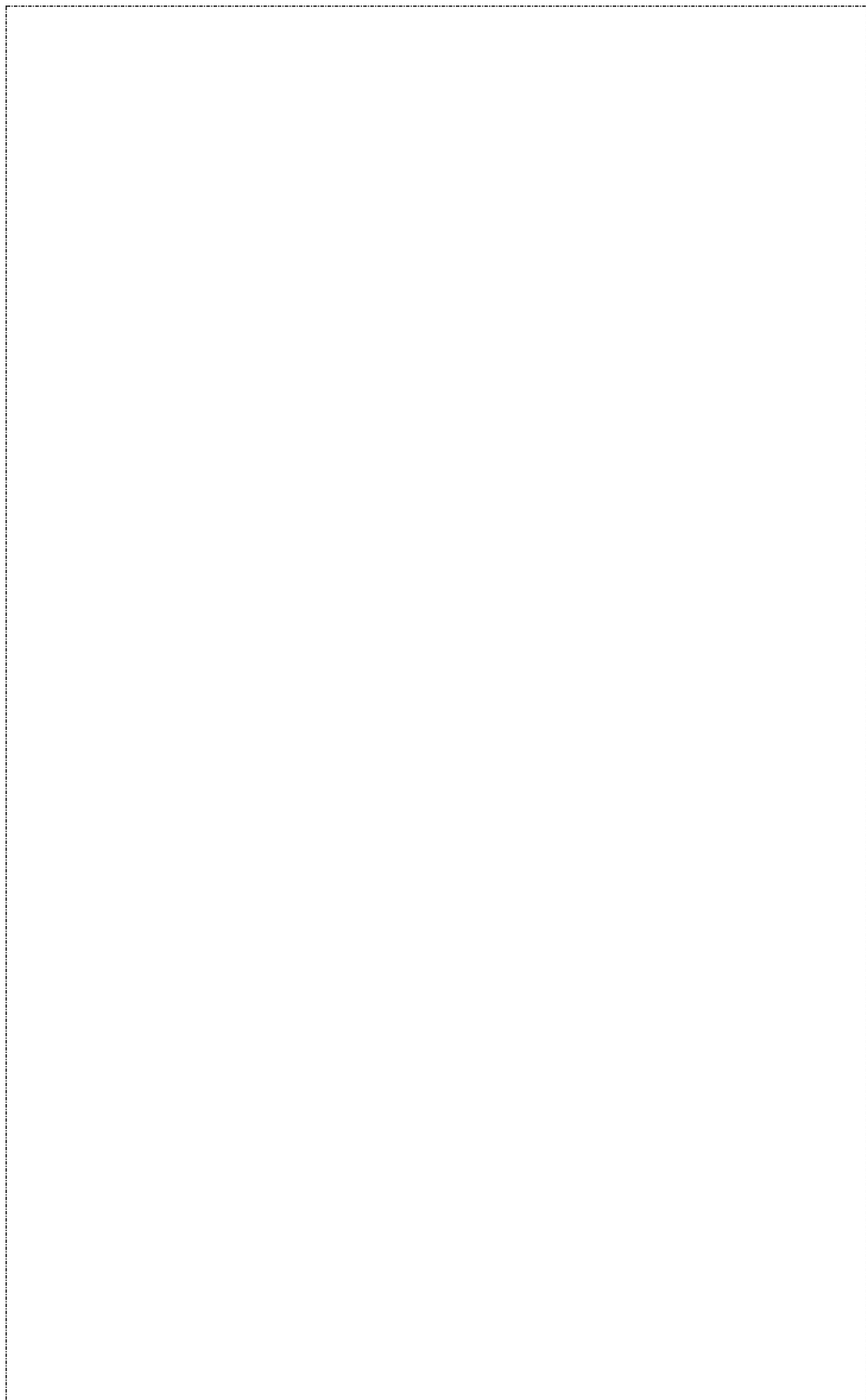
**Mr. Shivakumar Manohar**

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# TABLE OF CONTENTS

**Introduction to Down Syndrome**

**Chapter 1: Joy in the Storm** ..... 1-3

**Chapter 2: A Blessing in Disguise** ..... 4-6

**Chapter 3: Upside Down** ..... 7

**Chapter 4: A Roller Coaster Ride** ..... 8-10

**Conclusion**

**Authors**



# Chapter 1: Joy in the Storm

by Veeravalli Sarah Smily

Sujoy woke up suddenly from his deep sleep! “Oh my! I really thought it disappeared”, Sujoy sighed a deep sigh of relief while he shut the almirah! He dreamt that Bull wore his favourite spider-man T-shirt and ran into a deep forest. He reached for his glasses, took a second glance into the almirah, and calmed his racing heart. “It was indeed a nightmare, an awful, bad nightmare,” he whispered.

The time was 4 p.m. “Are you going to play with Roshan?” queried Radha, Sujoy’s mother. “I cannot miss my favourite pastime with my bestie”, replied Sujoy. “I packed some snacks for both of you. Share it with Angel too,” reminded Radha. “Off you go then. Remember the drill?” questioned Radha. “Of course, Mama! Smile when they stare!” You always remind me that, complained Sujoy as he picked his cricket bat and walked towards the playground not more than three blocks away from his home.

Even as Sujoy walked on his bright red trousers and a Panda T-shirt, with his most prized possession – Harry Potter glasses, Radha stood for a long time near the entrance, watching and appreciating how quickly he blossomed to a twelve-year old. Memories flashed before her like photographs: black and white and coloured.

Radha was an Economics Professor working at The Green House University, Patna. Her career was at full spring when she met, loved, and married Shankar. God gifted them with a bundle of joy, Sujoy. He was different from other babies, he was cuter with big, round eyes and spikey black hair. His hands and feet were so soft Radha could not resist cuddling him! Radha readily accepted this special gift from the Almighty and mothered him with care and love. But for Shankar, it took three months to realise Sujoy was no different than any other baby. When he finally accepted the fact, he became the best father Sujoy could wish for. Radha used to peep into the father-son fondling time, where Shankar would talk to Sujoy, say a hundred sorry’ s for not caressing him for the first three months and assuring him to support him from that time forth. Sujoy would respond with a chuckle, babble something, and smile broadly. Shankar understanding his baby-language always shed happy tears saying loud, “Thank you, Sujoy, for choosing us!”

“How time flew!” recalled Radha when she went into the kitchen to chop potatoes. She quit her job and became a full-time mother. Relatives became strangers and strangers became relatives in the long eleven years since Sujoy’s

birth. Though her colleagues and friends felt she should not sacrifice her career in raising a child, she held on to her motherly instincts. She never treated him as a Downs child. “He is a child with Downs,” she used to keep correcting when people addressed him otherwise. Reflecting, she wondered at her boldness and stubbornness! Shankar constantly supported her initiatives and applauded her learning. Even when she was an expert in Economics, she did not mind becoming a student all over again to learn everything about Down Syndrome. She refuted every myth about a child with Down Syndrome and proved with Sujoy as a live example about how the children with this condition can survive and thrive in this big world.



Sujoy is a happy kid. He brings joy wherever he goes. From playing with Bull, the dog, to watching Cartoons on Telly and listening to music, Sujoy enjoyed all his tasks. He is observant and alert when it comes to his favourite T-shirts. He would check, re-check and close the almira just for fun! He is also exceptionally good with painting. The first time he drew a cat like image with whiskers which covered the whole page. He was satisfied that the cat had long whiskers.

Radha and Shankar appreciated his initial efforts in sketching. Slowly, they motivated him to draw more than a cat. Now, he filled his room and the living room with his paintings. He likes gifting his art to his teachers and friends.

“I am back Mama! Angel did not come today. So, Roshan and I gobbled the cookies and went back to play” informed Sujoy. Radha looked at the clock. It was 5:30 p.m. He was back at home exactly as he promised. “Anything new to share today?” questioned Radha. “Yes Mama! I did 56 runs without a break and won over Roshan who did 49 runs!” reported the joyous Sujoy. “I am so happy for your achievement Joy,” replied Radha.



While he went to take a shower, Radha felt she should celebrate Sujoy's joy. He went through difficult trials and hardships in his short life due to his health and societal acceptance. Though he loved being around people and mingling with them, their stares and comments used to bother him from a young age. But being a boy with understanding, he started realising that what his Mama and Dada think about him is the ultimate and that he should not worry about pleasing every stranger.

Sujoy dreams big! He wants to climb Mt. Everest and wants to be a Pilot one day. Radha and Shankar are thankful to both the Almighty and Sujoy for choosing them as parents. They vow to themselves to stand by him in every storm that he might encounter at a later stage and are hopeful that their Sujoy will achieve everything he dreams of, in near future.

# Chapter 2: A Blessing in Disguise

by Dr. Lalita Joshi

“To succeed... you need to find something to hold on to, something to motivate you, something to inspire you.”

- Tony Dorsett (American Football Player)

Dr Lalita is an Obstetrician otherwise, Gynecologist by profession. She is a simple woman with strict principles. She is driven with honesty and a deep love for her second son Ashish, meaning blessing who was born with Down Syndrome, twenty-seven years back. Fortunately, Ashish was accepted by all their family members who refer to him as Lakshan Kobacha or lucky child. He has a dotting elder brother who would not tolerate a loud voice, let alone harsh words from anyone, including his own family.

In the good old days, let alone parents, even doctors did not know what Down Syndrome was. There were hardly any resources to guide or professional help to ease. Lalita's husband was a Cardiothoracic and a Pediatric Anesthetist, by profession. Though both were professional doctors in their fields, the term Down Syndrome was totally new to both.



Lalita had six consecutive spontaneous abortions before having a molar that is, an abnormal pregnancy which was a risk factor for birth of a child with chromosomal abnormalities. A Junior House Officer was the one who had suspected the condition while none of the senior doctors could. The facial features of their baby resembled that of a child with Down Syndrome. However, when Ashish was three years old, it was confirmed through the results from Karyotyping, that he had Down Syndrome. While the most common type of Down Syndrome is called Trisomy 21, which accounts for about 95% of the population incidence, Ashish had a less common type, known as Mosaic, which is a milder form of Down Syndrome that accounts for

about 1-2% of the population incidence. Ashish was in NICU for fourteen days before he could come home. Lalitha tried to breast feed him but could not produce milk. Her husband was a strong support during that testing phase. He had slept in a small Volkswagen car the whole night in the cold December month feeding Ashish every hour with an ounce of Lactogen milk.

They went to Australia for training and had met Dr. Stephen Horowitz who became their mentor and a dear friend. Dr. Horowitz also had a son with Down Syndrome. He provided them with the latest information on DS along with a book written by a Pediatrician Dr. Mark Selikowitz, Prince of Wales Children Hospital, Sydney and VCD on Early Intervention developed by Macquaire University. The book which she had brought back home, gave her all the information on how she could rear her child. The mentors and the book helped her immensely to take care of and to train her son bringing him to the present position – independent and confident.

When Ashish was five years old, he attended The South Point Boarding School in New Baneshwor. The school authorities did not know that Ashish had Down syndrome, as the parents had kept this matter hidden (for fear of him not being accepted by the school). Everything was fine, until Ashish was eleven years old. The school authorities realized that something was not quite right with Ashish and speculated that he might be having some learning difficulties. This was when Lalita spoke with the Principal and told him the truth that is, Ashish is a child with Down Syndrome. Instead of ridicule or embarrassment, to her surprise, Principal decided to keep Ashish and take on this as a new challenge. The teachers, other parents and children treated Ashish with a great deal of respect, often helping him with his homework and teachers giving extra teaching time. Ashish stayed at South Point until he was eighteen. He sat for his grade ten but could not clear in the first attempt. But in the second attempt, he got through, without any scribe. Ashish now twenty-seven years old, has a full life, likes to dance, plays keyboard, and has basic computer skills. Though he used to paint before, he is not interested now. Lalita continues to look for avenues where Ashish's real talents can shine and thrive. Ashish had home training from an occupational therapist couple of years from now, which has helped him to handle money and independent travel by public transport. He held a job as reception support for four years and discontinued, since the demise of his father nine months back. In Nepal there were no services specifically focused on people with Down syndrome until the Down Syndrome Association of Nepal (DSAN) was founded in 2006. *"If every child matter, every child has the right to a good start in life. If every child matter, every child has the right to be included. And that is so important for children with special needs."*

Lalita pays tribute to her mother, her elder sister and her husband for their unconditional love and devotion in rearing Ashish. She is thankful to orderly Tensing who used to be called as second mother, who had fulfilled the duties of a mother, when Lalita was at work.

She also feels blessed to have known Dr Rekha Ramachandran, though late, a driving force who inspired her in everything, to help Ashish in his further development, and move on, in life.

# Chapter 3: Upside Down

by Mrs. Thungambika

She made them better people. She made her younger brother compassionate and caring just like her. She had brought so much happiness into their lives. She has a wonderful sense of humor, is lovable and affectionate. Her smile is truly infectious. She has made her mother a strong and a positive person. One might be wondering who she is! She is the protagonist of this narrative. Her parents named her, Vanisha.

Vanisha was one month old when the pediatrician explained the parents about her Mongolian features and advised for Karyotyping test. Parents were complete strangers to the medical terms and conditions that were explained to them. She was their first child. The D-day had come, and the results were revealed. The revelation was shocking, and a state of denial veiled them. Since it was unknown and new, they could not comprehend that they had to face a day like that.

They went through various phases emotionally and mentally before they finally came to terms in accepting her as she was. Post acceptance, they had only two aims before them that is, making Vanisha independent and happy. After a long struggle, her mother accepted the situation and empowered herself with acquiring knowledge about the unwelcomed guest who became family, Down Syndrome.



Many doubts lingered in the minds of the parents – will she walk, will she talk, will she look different were few of the questions they let the time solve. It had not always been easy bringing her up with all the ups and downs! As the years passed by, a sixteen-year-old teenager evolved, destroying all the qualms the parents had had. Vanisha and her mother have a loving mother-daughter bond growing. People tend to think they are sisters.

Her mother gives credit to her supportive husband and family without whom it would not have been an easy journey. She feels the need to raise awareness about the challenges faced by people with Down Syndrome. She concludes, “we need to bring an awareness in the society about Down Syndrome, that, it is not a disease or some kind of devastating affliction.”

# Chapter 4: A Roller Coaster Ride

by Mr. Shivakumar Manohar

It was destiny that they had to meet. Shiva an introvert IT professional and Krithika an exuberant scientist had met way back in 2008. The polar opposites did not know what was instore for them. What started with a text message moved onto phone calls. They spoke and...spoke. They spoke as much as they wanted, thinking that the world is coming to end tomorrow. Love blossomed and it was time Shiva confessed his love for her over phone, which eventually was accepted albeit a few days later. In era where technology was helping everyone' cause their long-distance relationship flourished courtesy of GChat, Facebook, Skype and office emails and what not! Then came the D-day (of course, with all family troubles behind) which eventually geared them up to face the world together.

Nature has its own way of driving things in one's life. When Shiva was contemplating a move abroad as part of professional career, he was greeted with perhaps one of the sweetest news of all time. His impassive face still remained the same, but internally he was elated to know that his wife Krithika conceived and they were due for a baby soon. Then started the hospital journeys week after week, month after month and eventually the calendar turned to 20th February 2016. Beautiful little girl baby named 'Riya' stepped into their 'world'. Yes, she has been the world to them and will continue to be the world to them.

Upon birth, Riya was suspected to have some issue as doctors confessed, she looked a bit different in her looks. She had a flat nasal bridge; her eyes resembled the shape of 'almond'. Prior to delivery, there was signs of 'double bubble' in the scan. This was devastating news. Nevertheless, Shiva remained positive that all these troubles suspected will not materialize. He got in touch with his friends from medical fraternity to reassure himself. Then, what he feared indeed became true. Riya was confirmed to have been diagnosed with Down Syndrome (Trisomy 21 in medical terms). Riya was found to have a malfunction corrected through a surgical procedure (Annular pancreas) at day four of her birth. The only question that was going through his mind was 'Why me? Why has this happened to me?'

It was a painful journey to go through, especially considering that he always wanted to have a daughter. However, it seemed as though god had planned it different for him. It took few days for him to regroup himself, post which he decided to let Krithika remain ignorant of Riya's condition. He did so to ensure that she does not brood over it but rather spend precious time with their newborn, in all happiness.

Eventually, after six months of birth, the news of Riya's condition was disclosed to Krithika. It was a difficult discussion between the couple, and it was hard to take the news with tears flowing uncontrollably from either side. They had their differences and similarities in grasping the situation, but they remained aligned to one important thing – 'Riya is ours and we got to do what it takes.'

As they say, you gain a lot of exposure and experience through travelling. They as a couple travelled through lots of people, met a lot of doctors, barged into lots and lots of parents who were going through the same situation. But the real turning point came in the form of Rekha Ramachandran. Rekha ma as she is fondly called is the president of Down Syndrome Federation of India (DSFI). To say that, she is the epitome in positivity would be an understatement. During the times when medical advancements were not great, she taught how to bring up a child with Down Syndrome and transform the child into an independent individual with no limits symbolized her grit, confidence, determination, and strength. Meeting Rekha ma and realizing that it's indeed possible to turn things around made the new parents mentally strong. From then on, there was no looking back!

Riya became a frequent visitor to Mathru Mandir (Based out of Chennai) along with Shiva and her grandma. She was put through physiotherapy from eleventh month of her birth. As a part of daily routine, she was made to do some simple exercises, exposed to lots of flash cards of objects around her. Shiva and Krithika took a unanimous decision to have an occupational therapist visit home, so that early intervention is not compromised. Riya attained her milestones with a bit of delay as expected. She attained head control by six months, started sitting on her own by nine months, and crawled only after a year. She started walking by one year eight months, which reflected the fact that her body was responding to all the therapies.

Riya was enrolled for speech therapy sessions where she was intervened for anticipated speech delays. She was also enrolled in a play school at two years of age with a view that she will learn from the peers, socialize well with her friends, inculcate discipline and bridge the delays that will come with speech development. Riya soon became a star in her school. Since she was very friendly, everyone liked her.

Meanwhile once the goal of walking was achieved, the visits of the occupational therapist stopped. All therapies were integrated with day-to-day life routines. Now, the focus was more on improving her fine motor and gross motor skills. She indulged in lots of play activities, which improved her fine motor skills (handling beads, painting, coloring, flipping pages, handling coins, manipulating objects, playing with clay etc.). Her gross motor skills were getting fine-tuned as well with activities on strengthening the trunk.

Both Shiva and Krithika understood the need for medical checks that needs to be done. Riya was screened for her thyroid levels every six months. They had a yearly review with child surgeon (w.r.t surgery she went through), who have done their heart ECHO and confirmed to be good along with the yearly review of eye and ears for any anomalies. These medical checks are indeed necessary to identify any medical issues.



As days rolled on, Riya started unleashing her potential. She was quick to grab concepts, though she warranted an additional bit of help. She improved her vocabulary, started uttering one or two words, and was able to communicate her needs often than before. The speech therapists further tapped her potential and through cognitive method, she spoke her first sentence (five words) by three years eight months. Meticulous

planning in teaching adverbs, nouns, verbs and enabling her to reason out things made her excel in her day-to-day communication. She earned good reviews in school and she was knowingly or unknowingly preparing herself to get integrated into a mainstream school.

Riya was screened in four different top-notch inclusive schools in Chennai and she came out in flying colors. All schools were open to onboard Riya, but then Shiva and Krithika thought through and chose the school expected to improve her in all angles as she moves down the years. So far at four years six months of age, their choice is vindicated.

The obvious learning over the years has been – nothing is impossible; have a vision with appropriate effort spent consistently; medical checks are not to be missed; keep working on the kids; challenge them with various things; never underestimate them; take help from professional and fellow parents; have a daily plan in place and execute them without any slippage; travel a lot; expose them to as many people and environments as you can.

Both Shiva and Krithika have firmly overcome the initial fears of having a special child. They now understand Riya better and are taking steps to make her independent. They are trying to create a positive web around the child, have a fair understanding on what needs to be done and what they can expect in future. The world is full of roses for them!



## CONCLUSION

This Book titled **‘The Ups and Downs of our World: A Collection of Narratives’** is a compilation of the imagination, creativity and experiences of the authors. Though each of the authors hold different occupations in their professional lives, their passion remains the same that is, *to make this world a better place for the children of Down Syndrome to survive and thrive*. The narratives were stringed with love and responsibility towards the readers. The main gist of all the narratives reflects around the concept – strong and healthy *roots* produces *fragrant flowers*. While the *Parents or the Family* represents the *roots*, a *child with Down Syndrome* represents *fragrant flowers*. The love, care, attention, understanding, co-operation, and encouragement received by the children with Down Syndrome from their family and parents inculcates positivity and brevity enabling them to face the real world.



# Authors

**Ms. Veeravalli Sarah Smily**  
Assistant Professor  
MITS.

**Interested in:**  
Singing,  
Writing Poetry,  
Playing Badminton,  
Painting.



**Dr. (Rtd. Br. Gen.) Lalita Joshi**  
Senior consultant Obstretician and Gynaecologist  
Founder of Down Syndrome Association of Nepal.

**Interested in:**  
Music,  
Reading.



**Mrs. Thungambika**  
Home maker

**Interested in:**  
Music,  
Drawing.



**Mr. Shivakumar Manohar**  
Project Delivery Manager  
Cognizant Technology Solutions.

**Interested in:**  
Sports.



