

My daughter Selena was born in a private hospital on April 12, 2002, a beautiful spring day in Izmir. It was the doctor's choice to have my daughter born via caesarean section. Selena was born as a healthy girl, weighing 4 kilos and 54 cm tall.

Everything seemed to be fine, but when she turned one year old, we went to our paediatrician thinking that she was delayed in starting to walk. Our doctor said this was not a significant delay and Selena was able to walk at 18 months. She had already started talking when she was one year old. She started saying "mom", "aunt", "popsy", "one", "two" and the names of her relatives around her. On her second birthday, her grandmother asked her, "How old are you?" and she turned to her and made the "two 🖐️" sign with her hands and verbally replied, "Two." In the summer, when my daughter was two and a half years old, her stereotypic hand movements began. She stopped using the words she used to use, her facial expression became dull and she was no longer saying new words. We went to the paediatrician again. The doctor said that he thought there was no problem, but that we could do further tests such as EEG and MRI at the end of the summer. But I was noticing negative changes in Selena. At the end of the summer, EEG and MRI were taken. The EEG was not normal, and there was no problem in the MRI. Of course we were sad. We reached many doctors and in the meantime we received a diagnosis of autism. Like most girls at Selena's age with Rett syndrome, we have received different diagnoses over the years. We started intensive special training and antiepileptic medications. In the meantime, we received different diagnoses such as autism, pervasive developmental disorder, mental retardation and Landau Kleffner Syndrome (LKS) until we received the correct diagnosis. But I, and my family who are my biggest supporters, have never been too obsessed with diagnosis.

Once we got over the heavy effects of the deep sadness and shock we experienced with the diagnosis of autism, we focused on supporting and improving her physical and mental development. When my daughter was three and a half years old, we went from Izmir to Istanbul in search of a more specialist doctor, better special education and therapy, as we all experience. We rented a house and lived there for two years. Because I observed Selena well, I felt that diagnoses such as autism and mental retardation were not correct. Our doctor in Istanbul suspected that my daughter might have Rett syndrome and sent us to a university for genetic testing, but the result came back negative, saying "No known mutations were found." I guess genetics science was not at the current stage in those years. As a result, Selena did not have Rett syndrome according to the conditions of that time.

Meanwhile, in 2007, when Selena was five years old, we went to a hospital in St. Louis, accompanied by my brother. But again, we came back without a diagnosis of Rett syndrome. No genetic testing was done. MRI and EEG were taken. In fact, the nurse who came into the room after the EEG scan said, "The result is great, we don't even accept patients with epilepsy at this level." We went there on a 26-hour flight. We flew to Izmir - Istanbul - Munich - Chicago and St Louis. Our return was again with four flights, one from Washington. Our outbound flight was very difficult, but on the way back, we took the front seat and I spread a blanket in the space in front of us and laid Selena down. The long part of the flight went easily this way. During the flight, no one even turned to look at us, everyone was very understanding. A female passenger even held my hands while I was taking Selena to the toilet and said to me, "You are very tired on this flight."

Then we returned to Turkey. We continued to participate in special education programs and therapies. Meanwhile, we started going to a big gymnastics club. Selena took private gymnastics and swimming lessons. She loved her teacher very much. And with that love, my

daughter deliver a performance that surprised even me. Our children are very happy and successful where they feel true love.

Meanwhile, my daughter's school life started. Thanks to my efforts, a little luck, and meeting kind-hearted people by chance, Selena completed her eight years of basic education in the classroom where regular students were educated. This benefited her a lot. I think the happiest child in class was Selena. She was accompanied by a shadow teacher at school. She was a young child development teacher. The children and their mothers were very supportive of Selena.

By the way, we did not worry too much about having the syndrome. We tried to live a normal life. We even traveled abroad with Selena. Sometimes there were very difficult moments, but we also had very enjoyable and happy memories. We went to the Greek islands of Lesbos and Chios by ferry. We traveled to Selena's uncle while he was living in Dubrovnik, Croatia. We went to Bosnia and Herzegovina many times with two connecting flights. We wanted Selena to experience mountain skiing there.

Meanwhile, our EEG results were improving during our control examinations. We stopped antiepileptic treatment at the age of 14 by reducing the dose. There were no problems, but in 2017, Selena slipped and fell at home, due to the surface. She had a seizure and we went to the hospital. Afterwards, we went to Ege University Hospital, close to our home in Izmir. When our neurologist, Ms. Sanem saw Selena, she suspected that she might have Rett syndrome and recommended genetic testing to Selena again. The results came and we learned that Selena had Rett syndrome. Now, the puzzle is completed. Rett Syndrome was not a milder syndrome than autism or LKS, but knowing the truth and receiving the correct diagnosis made us very relieved. In this way, the questions that have been in my mind for years have become clear.

Then I reached out to your current association president, Mr. Burak. He helped me a lot to quickly learn about the syndrome. I tried to support the establishment of the association. The existence of an association was very valuable in terms of meeting people who were going through the same things as you.

Afterwards, even though years had passed, I intensified my research when we received the correct diagnosis. One day I came across an article by Aleksandra Djukic from USA. Most of her sentences were the same sentences I sometimes say to doctors. She said that children with the syndrome had the ability to learn, but they could not show it because the syndrome suppressed it. I never had any doubts about Selena's ability to learn. In fact, from a young age, she even understood and laughed at adult jokes.

MD Djukic was director of the Montefiore Rett Centre in New York. We contacted the hospital and went to New York in September 2019. Again, it was a trip where we changed continents. Selena had grown up and was in better physical and mental condition, but we were still experiencing the troubles and difficulties of Rett syndrome. Especially as she entered puberty, her sleep problems increased significantly. Our second trip to America was, fortunately, only with two connecting flights. Business flight prices were too high for us at that time. So we decided to create our own business flight 😊. Because we experienced how difficult it is to fly in economy class on our previous trip. So, we were three people, but we had purchased six seats

in economy class. In this way, Selena would be able to lie down and sleep, and we would travel more comfortably. And so it was. By the way, for this trip, İpek, the daughter of my friend Özlem, who has been my daughter's paediatrician since the age of seven, volunteered to support us both with my insufficient English and for the difficult journey. Two young girls and I met on the day of the flight. Our trip had begun. Since Selena is now 17 years old, we showed her movies and animal documentaries on the screen on the plane, and when she got tired, she could lie down and sleep.

We arrived in New York. The potty training issue was resolved when Selena was seven, but I put a diaper on her as a precaution to keep her comfortable during the trip. On our previous long journey, I did not put a diaper on her because I was more inexperienced, but now we felt more comfortable doing so. When we arrived at our hotel, she went to the toilet then.

Our doctor's appointment was in three days. A young man named Hasan, a former employee of mine, met us at the airport. It had been a year or two since he moved to America. His presence was very good for us. Hasan turned our health trip into a touristic trip as well. We visited Central Park, Brooklyn, which Paul Auster described in his books, Manhattan, Bronx where our hotel is, everywhere. One night, I think on our first night, while İpek, Selena and I were resting in our hotel room, we suddenly wanted to call an Uber and go to see Times Square. And we did something crazy: We did this! I still cannot forget Selena's reaction to the bright and showy scene of Times Square at night, looking around with happiness and curiosity, with surprise and maybe a little admiration! It was incredible! Selena was actually very adaptable during our trip to America, we went to New Jersey with her and visited one of the largest outlets in America without skipping a single store, and Selena loved shopping as a young girl!

If Selena was in a good mood, we would eat hamburgers or pizza at various restaurants, if not, in our hotel room. The hotel we stayed in was very large and comfortable. It was also very good for us to have a Starbucks right below our hotel. There were various restaurants around the hotel where we could eat, stores where we could shop, and it was an area closed to traffic. The hospital recommended us there for accommodation.

Selena had a big sleeping problem, and when jetlag was added to this, we started to feel very tired. Fortunately, our appointment time with MD Djukic finally came. We went to Montefiore Hospital's Rett Centre. Dear Aleksandra examined Selena in detail. She told me about the current situation in the treatment of Rett syndrome that day. She explained that scientists now think Rett is a treatable syndrome. In fact, I was explaining quickly and excitedly: "Selena is actually very smart, she knows everything, she even knows numbers and colours in English!" Then Aleksandra smiled and said, "Oh, mothers are always so excited and talk a lot like that." Because that's exactly what she was talking about in her articles. There was a doctor in front of me who already knew Rett syndrome. We even met the language therapist and physiotherapist at the centre. They also evaluated Selena. "Selena looks fine, but still get a routine heart exam," Aleksandra said. She also suggested that she be examined by an endocrinologist, because Selena was not menstruating and had gained weight. There she weighed 74 kilos. When we returned to Turkey, we were examined by an endocrinologist and we overcame this problem, and my daughter was able to lose weight.

Today, Selena is 1.70 tall and weighs 58 kilos. She managed to lose weight with a healthy diet, the medication she took to have regular menstrual periods, and with exercise and walking.

Finally, the doctor also gave Selena a medicine for her sleeping problem, and all three of us slept very well in our hotel room that night. We had some very difficult moments there, but later on, those were the times we laughed the most. We did not have much trouble on the way back either. She spent most of the flight from New York to Istanbul sleeping.

We have come to the end of the adventures of our very exciting and sometimes challenging trip to America. Going on a transoceanic journey might have been challenging and crazy, but it was also exciting and full of humour.

I would like to add that it is not always easy to deal with all of it as a single mother. I have moments when it is very difficult, but I get my strength from my daughter. I am also grateful to my family and friends who have always been by my side during my difficult journey with Selena. I am glad to have you.

I hope that in the near future scientists will find a solution to this syndrome and all our angels will regain their freedom. Endless thanks to the doctors, geneticists, pharmaceutical companies and especially the associations that give us strength.