

Education, Culture, Sports, Science and Technology Minister's Award

"Let's Hold Hands, Kota"

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My younger brother, Kota, has a big head and sloping shoulders and is always smiling. He has Sotos syndrome. Babies born with Sotos syndrome have big heads and bodies and show delays in development. Persons with Sotos syndrome all have similar features. In most cases, the syndrome is said to arise from mutation.

On August 13, 2012, my brother was born. I stayed at home with my grandmother and heard that my brother was born healthy without accident and was very happy. I was so excited that I could not sleep well that night. The next day, I first met him.

Looking at my brother sleeping soundly in an incubator, I stretched up and waved my hand, saying "I am your sister." As lots of tubes were connected to my brother, I could not hold him that day. It was after discharge from the hospital that I could hold him in my arms for the first time. I sat on futon and widened my arms to accept my brother. I remember that I kept talking to him, saying things like "I am your sister." and "Glad to see you."

After I entered an elementary school, I gradually noticed my brother's disability. I wondered why my brother only said "A" or "Nn," while his peers remembered words and talked many things. I asked my mother. Then, my mother told me about his disability. I was surprised at first but did not care so much and continued enjoying time with my brother. However, as I grew up, I came to recognize differences in development between my brother and his peers and came to mind people's eyes when going shopping with him. I gradually kept a distance from my brother when I walked with him. I wanted to walk with him side by side in my mind, but I could not have courage while being aware of people's eyes.

One day when I was a seventh grader, I went shopping with my brother, my cousin, and my mother. I waited for my mother and my cousin to finish their

shopping by walking around the store with my brother. He had come to understand things gradually, and I was a little bit lazy. Then, my brother suddenly grabbed his favorite sweets and was about to leave the store. I hurriedly took back the sweets from him and pulled his hand, but he sat down on the spot and started to cry loudly and struggled. My head went blank and I stroked my brother's back gently to calm him. This was all what I could do for my brother who was crying and struggling. Just then, my cousin noticed this trouble and went to call my mother. I felt relieved and noticed for the first time cold eyes cast by lots of people who were looking at me and my brother and the existence of people who entered from the entrance and hurried away as if avoiding us. I was filled with sorrow and powerlessness. As soon as I got into the car, tears came to my eyes and I could not stop them. My brother was playing with hands with my cousin as usual as if nothing had happened. My mother drove the car without a word.

That night, I was called by my father and I told him what happened at the store and what I thought at that time. After listening to me silently, my father said to me, "You learned a lot today. Your brother may differ from other children who were at the scene today and other second graders, but he came to us to be a family member as he thought he would be safe here. So, you should say with confidence, 'He is my brother that I am proud of!'" I was deeply moved. After that, I went to my brother's room. The tears fell naturally, but this time, they were heartwarming tears. Seeing my brother sleeping soundly, I recalled the time when I held him for the first time and the words I uttered to him. "I am your sister. I will be always with you to protect you." I uttered the same words to him in bed and made a commitment to "cherish my brother throughout my life."

From then on, when I go shopping with my brother, I tightly hold hands with him and enjoy talking while walking. If my brother becomes violent, I ask my mother for help without getting upset. Then, his peers and elderly people who see my brother sometimes speak to us in a gentle manner. I noticed that not all people cast cold eyes on us or hurry away from us.

Since that day, I think that I have become able to recognize the reality of people and society by walking hand-in-hand with my brother. Not everything is pleasant, but I came to feel the warmth and kindness of other people and I realize my own growth together with my brother.

Someday, Kota and I will have to release our hands and live a separate life. I

hope that, until then, I would be able to create a society where all people, including Kota and other people with disabilities, can live proudly with peace of mind.

Today as well, I will walk forward joyfully but strongly, while holding hands with Kota and enjoying talking.