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Messages from an Experienced Mom by Kan-chan

“A Brave Baby”

People say that babies with Down syndrome are only born into families that have the ability to raise them.

I was chosen.

I used to think like this, but these days I have a different story:

Out of 1000 babies who are about to be born,
one of them will be born with a disability.

All of the babies feel hesitant, but one brave baby raises his hand.

“If there are no volunteers, I will be born with a disability
because I know that having a disability does not mean I will be unhappy.”

God is touched by this baby,
and brings him into the world with a disability and lots of happiness

In the hopes that he will meet his family
who will love him very much.

This baby’s name is Moco, and he is my son.
Moco chose to be born with Down syndrome
because he is my brave son.

Your brave baby descended from heaven to be with you and your family.
Raise your baby with lots of love.

*From Kantaro’s Blog Kyuukei Sokushin Iinkai on July 30, 2007
Moco was 5 months old at the time this was written.

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Messages from Experienced Dads

Dad of 3-year old son, Sosuke

I naturally assumed that my child would be born healthy; so, I was very shocked to hear that Sosuke had Down syndrome and a medical issue. Looking back, I realize that I was worrying about minor issues.

Now, I just want lots of people to meet our boy Sosuke who was born with a “unique advantageous characteristic” called Down syndrome.

Sosuke is the center of attention in our family. His smile always makes me feel better when I return home after a hard day at work.

Sosuke has many obstacles to overcome, but he has helped me to realize that we will get through each of them together as a family. Our family has become much stronger since Sosuke was born. Thank you for coming to join our family, Sosuke.

Rika’s Dad

Rika, who was a long-awaited girl, was our third child. When I found out that she had Down syndrome, I did not know what the future would hold for her. I worried about many things, such as her schooling, her career, and what other people would think of her. However, looking back now I can say with no doubt that the days I spent making an effort to behave in a cheerful manner for Rika and her brothers were definitely happy days. Even now I don't know if I have accepted my four-year old daughter’s disability... I don’t really even understand the difference between accepting her and not accepting her. All I know is that the life I have with my five family members including my daughter is a treasure.

This is what I think. Every step that you take “now” will create your future. I hope that you will cherish the idea of “living happily” as opposed to wondering whether or not you “will be happy” when your child is born.

Please live happily with your family “now.”

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Messages from Experienced Dads

Hiro’s Dad (Hakken No Hiro-san)

It’s been 8 years since my son was born. I have had many experiences during these past 8 years. The most worrisome time for me was when my son was a newborn. At that time, I was informed by the doctor that my son not only had Down syndrome but was also hearing impaired. My wife and I cried many times after hearing this. Fortunately, those worries are no longer a part of our lives.

For many years I had to leave work quite often in order to bring my son to the hospital. Gaining understanding from my colleagues about why I had to leave work so often was essential. Since Hiro was born, I have been constantly busy with one thing or another. Looking back, I feel like I was always trying to figure out what I could do for my son and my family as a father.

I still feel like I am battling with my feelings of incompetence every day (and I lose in most cases), but my family is living happily together now. Sometimes I feel a lot of stress from work, but I hope that our families can find a way to get through the difficulties we face.

B's Dad (Susshii-san)

My daughter who has Down syndrome was born in 2008. I knew that people with Down syndrome have characteristic facial features. This is what I thought about the moment I saw my daughter's face after she was born.

Until receiving a definitive diagnosis, I would tell myself, "She looks like she has Down syndrome" one minute and then tell myself, "No, no. She looks like a typical child" the next. I did this over and over again.

Once I received her diagnosis, however, I decided I would be frank and open with everyone about my daughter. After doing so, I found that there was a person close to us who has Down syndrome, and I was able to obtain information from an unexpected source. I was very lucky because these experiences broadened my horizons.

People often say to me that having a child with Down syndrome must be "difficult." However, I believe parenting any child is difficult. My wife and I do our best to raise our child just like most other parents who work hard to raise their children.

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Messages from Siblings

My Treasure

Iori Otani (She was in the 2nd grade when she wrote this.)

My treasure is my 1-year-old brother

His name is Kotaro

Kotaro was born when I was in kindergarten

Kotaro is small but he cries loudly

When I hugged him soon after birth he smiled at me

He was so cute

I want to take good care of my brother

He was born with trisomy 21 and one more chromosome than others

So he grows slowly

But my brother is cute and I am very happy he was born

My Little Brother

Riko Ito (She was in the 2nd grade when she wrote this.)

A, I, U, E, Otouto (My brother is) very cute
KA, KI, KU, KE KOrokoro (Rolls) over in bed
SA, SI, SU, SE, SOrosoro (It is almost time) for milk
TA, TI, TU, TE, TOKidoki (Sometimes) he cries
NA, NI, NU, NE, NONbiri (Relaxing) nap time?
HA, HI, FU, HE, HONtouni (He is really) adorable
MA, MI, MU, ME, MOusugu (Soon) he will be able to sit up
YA, I, YU, E, YOshiyoshi He is a (good boy)
WA, I, U, E, Onamae (His name is) Yuto-kun

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Messages from Siblings

My Older Sister

Daichi Ito (He was in the 8th grade when he wrote this)

Have you ever heard of “Down syndrome?”

Shortly before I entered elementary school, I went out alone with my mother for the first time. I forgot where we went, but I remember that the last thing we did was to eat a meal together at a restaurant. At that time, she told me that my older sister has Down syndrome. It was difficult for me to understand at the time. I remember my mother telling me that once I started elementary school, I might feel offended by what some people say about my sister. She told me, however, that I should act openly and confidently about my sister because we didn't do anything wrong.

When my sister was younger, she was hospitalized a lot when she got sick. She has reduced muscle strength throughout her body. As a result, things that are easy for us to do are often difficult for her. Since I don't understand the difficulties she faces, I get annoyed by how long it takes her to do things. Her stubbornness also upsets me. However, I think any siblings I had, even if they didn't have a disability, would sometimes irritate or upset me. I am sure we would fight as well. My sister is persistent. She works hard to do the things she decides to do. She is very patient. She never speaks badly about others and she always finds good things to say about them. She is quick to forgive even if she gets bullied. She always has a positive mindset and has the courage to take risks. Every year on my birthday, she gives me handmade presents that she has put a lot of effort into making.

My sister doesn't have Down syndrome because she or my mother got sick. I heard that 1 in 1000 babies are born with Down syndrome. There is a chance that I could have been born with Down syndrome.

My sister was just born on behalf of 1000 babies, but many people do not understand that.

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My father never gives special treatment to my sister. He scolds her when she does something wrong. He praises her when she does something good.

My mother was shocked when she found out about my sister's disability. She cried every day and rarely left the house for over a year. However, my father took my sister everywhere. I respect him for that.

Since I was born, I have never seen my mother cry. I heard that my mother decided since she had already cried a lot, she was never going to cry again no matter what happened.

I am lucky to have such parents. My parents did not choose to send my sister to a class for special needs. She spent her elementary and junior high school days in regular classes. She was very happy to be with her friends, worked hard on the things that she could do, and studied even harder than I did.

I knew my mother did research late into the night every night in an attempt to learn about laws and obtain information that might benefit my sister. However, I hated seeing my mother apologize to people who said rude things to my sister. I thought it was wrong that it was so difficult for my sister to be in a regular class with everyone else just because she had a disability. I was also frustrated by this. If my sister didn't spend time in the same class as everyone else, then I don't think her classmates would ever understand her. I think it is easy to understand how we can extend a helping hand to those who are in wheelchairs. However, people who have Down syndrome have individual differences just like we do. This means that they have different needs in regard to support as well. This is why I think it is important for people to gain an understanding about disabilities and actually get to know people who have disabilities. I don't think people with disabilities and people without disabilities should be put into separate categories because all of our lives are all equally important.

*This was taken from an essay that won first prize in the Junior High School Category (Kanagawa Governor's Prize) at the 40th Essay Contest on Welfare in Kanagawa Pref. (2016)