

Prime Minister's Award

I Will Be a High School Student Along with Friends

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“I will be a high school student along with friends.”

This is my goal for this year. I have set this goal because it is never going to be easy for me to become a high school student.

I am fighting against an intractable disease called congenital epidermolysis bullosa, which makes the skin and mucous membranes so weak that they can be damaged by even the slightest irritation. My whole body is always covered in sores, which constantly hurt and itch. It takes at least three hours every day to apply an ointment to the sores all over my body and change my dressings. After I bathe or when the sores are aggravated, the same process sometimes takes more than five hours. My mother and grandmother have been practicing this treatment ever since I was born, never missing a single day. Because of this, both my family and I constantly suffer from a lack of sleep.

Even in such a situation, I have never wished to be absent from school. This is because I feel happy to be at school. All that the teachers tell us in our classes and all that I newly learn deeply interests me. All my classmates are kindhearted, and make me feel happy to study or talk with them. No matter how sleepy I am, I always feel refreshed when I am in school. This is because I believe that I can connect with my classmates by attending school and studying. Therefore, I fervently hope to enter high school instead of giving up my student life when I graduate from junior high school.

However, what I found was a harsh reality. I have so far visited a number of high schools, where teachers treated me in a cordial manner. I was surprised at the large school buildings or grounds compared to those at junior high school. Seeing well-equipped special classrooms, I felt the strong desire to study in such a wonderful environment. However, many high schools do not even have elevators which are indispensable for me who live with an electric wheelchair, so I have a limited choice of high schools I can enter. Furthermore, few schools have positive attitudes toward accepting students with disabilities. Some schools refused to enroll me, imposing on me the condition of entry that I must be able to do everything for myself. Although I go to a university hospital for rehabilitation and receive guidance from a therapist there so that I become able to do many more things for myself by devising effective methods, there are some things that I just cannot do. Teachers, special assistants and classmates help me in doing such things at junior high school. My heart is again filled with gratitude toward

those people for enabling me to live a satisfying school life. However, when I went to look around high schools, people at most of the schools told me that they could not support me in the same way as at junior high school because high school education is not compulsory. I have serious concerns about whether I would be able to lead an independent life at high school without any support. With entry to high school just around the corner, I have been made acutely aware that there is a huge gap between my “ordinary” life and the “ordinary” lives of people without disabilities, and faced a harsh reality I have never experienced before.

Nevertheless, I hope to enter high school and continue my studies. I never want to live my life confined to my house because of my disability. I have so far studied at a local kindergarten, elementary school and junior high school, have interacted with many people, and have been supported by many people. To repay all their kindness, I have made determined efforts. I would not like to stop making such efforts at this point.

“I want to have lots of friendships. I want to accumulate various experiences. I want to find out what I’m capable of. I want to search for what I really want to do.”

I have high expectations for my life at high school and the aspiration to tackle new challenges there. I hope to work based on such experiences at high school, and to carve out a future as a person who continues to participate in society.

My rehabilitation therapist told me that a law called the “Act for Eliminating Discrimination against Persons with Disabilities” had been enacted, and this act provides that efforts shall be made to give requisite and rational consideration to persons with disabilities. However, can it be said that the provision has been put into practice? I have been refused admission without taking an entrance examination. I have been told that no support will be offered to me. My mother has said that, if I cannot expect anyone’s support, she will accompany me to high school every day. But I do not want to impose a greater burden on my mother, who can have little time for herself even now. I hope that our society will become one where even people with disabilities can be sure of receiving a higher education as long as they aspire to study.

Many people have denied my hope in various situations, saying that they cannot accept me because there are no precedents like me. This is probably because there are only a tiny number of junior high school students fighting against intractable diseases in the same way I am. But I cannot give up this hope of mine just because there are no precedents. If there are no precedents, I myself will create a precedent. I want to be a high school student in an electric wheelchair, along with friends.