Little angel OLIVIA SANCHAREE NABONEE suffering from SMA needs support to continue her treatment

OLIVIA SANCHAREE NABONEE
Age- 2.5 Years

2.5 years old Nabonee is suffering from SMA (Spinal Muscular Atrophy- type 1). She is the 1st SMA patient in Bangladesh who is receiving medical treatment.

SMA (Spinal Muscular Atrophy) is a rare genetic disease that robs people of physical strength by affecting the motor nerve cells in the spinal cord, taking away the ability to walk, eat, or breathe. It is the number one genetic cause of death for the children who are suffering from SMA.

Spinal Muscular Atrophy (SMA) causes muscle weakness and progressive loss of movement. It is caused by deterioration in the nerve cells (motor neurons) connecting the brain and spinal cord to the body's muscles. As the link between the nerves and muscles breaks down, the muscles used for activities such as crawling, walking, sitting up, moving the head and even swallowing, become progressively weaker and shrink (atrophy) gradually.

We could identify some symptoms when our Nabonee was 25 days old. As our first child was died with having the same symptoms, we were aware and careful about Nobonee. We immediately went to the hospital and the physicians suspected that she has SMA. We then went to India and had the DNA tests. The results of the DNA tests confirmed that Nabonee is suffering from most critical type of SMA (Type-1).

Nabonee at the age of 2 Months

Nabonee's Sister Dhriti

Almost 10 years back our elder daughter Dhriti died at the age of 5 months with the symptoms of SMA. We could not identify her SMA by genetic tests due to lack of awareness among doctors and hospitals.

Nabonee at the age between 3 months and 9 Months.

It is very difficult to describe in words what we felt when we realized that our daughter is an SMA patient. We could not save our first child with all SMA symptoms and our younger daughter was also suffering from most hazardous type of SMA (type-1). We were really helpless. We thought that like our younger daughter, the little girl would die without any medical treatment because it is almost impossible for any family to afford the prescribed treatment of SMA.

Our actual struggle started then. We were informed that only 3 approved medicines were available in the world and that the acquiring of the medication needed millions of dollars. It is next to impossible for any ordinary individual to bear the cost of the treatment. As SMA is a rare disease, we thought that there is a possibility of getting support from medicine manufacturing companies for SMA. We communicated with Roche Bangladesh Ltd. that produce one of the approved medicines named Risdiplam. After continuous struggles of four months, we finally received the medicine and the subsequent treatment of Nabonee started. We are profoundly thankful to Roche Bangladesh and Dhaka Shishu Hospital, especially Dr. Saoli Sarker for their unlimited sincerity and dedication.

Nabonee started receiving oral medicine of SMA (Risdiplam)
On 20 March 2022

Before starting medication, her body was becoming soft like cotton. She was losing her strength of eating and stop breast feeding. But after getting medication her Power start regaining.
She is much better now. She sit for a while without support. Day by day she is improving. We hope that with the help of people and medication, she will be completely fine someday. We will brought her in such a way that she will dedicate her whole life for the betterment of whole mankind. She will remember all of those who contribute to make her life easier.

Before Receiving Medicine

After Started Medication

SMA patients are usually very much talented. Their power of graving different knowledge is much better than any other normal child. Nabonee is now only 2.6 years old. At this age she can sing more than 50 songs (English, Hindi & Bangla) at accurate tone. She can memorize more than 50 rhymes & poems. She can count 1 to 110, identify colors. If she listen a tone once, she never forget it.

We really believe that if we can continue the treatment of our Nabonee, she will be completely cured. We want everyone to collectively extend a helping hand for our daughter's treatment.

This situation is not only for my family, but for every family that has SMA patients facing similar situation. One and only desire of the parents whose children are suffering from SMA is to keep their children alive. They agree to go to every possible door for collecting fund to keep their children alive. Like all other parents, we also want to keep our daughter healthy by every possible ways. SMA patients need a lot of supporting devices and medicines which are also expensive. A middle class family like us cannot afford these.

We are praying to everyone to help us to continue the treatment of our daughter. It will be your most benevolent work of your life.