

## CureSMA Bangladesh

Bangladesh



[www.curesmabangladesh.org](http://www.curesmabangladesh.org)



**Hasan Mahmud**

[hasanf14@gmail.com](mailto:hasanf14@gmail.com)

### 1. About

Cure SMA Bangladesh is a registered public charitable foundation. It is a distinct, apolitical, non-profit, non-sectarian entity. We support SMA families through accurate counselling, rich resource pool, patient advocacy and various direct family support services. We are extensively working to empower SMA patients and enabling them to access existing services. Currently we are working on making a reliable statistic of SMA patients, as no party in our country has complete information or statistics regarding SMA.

I am the Vice President of the organization. I represent the patients and as well as the Cure SMA Bangladesh team, as patient advocate.

### 2. Mission

Our organization's aim to ensure access to treatment facilities and ease access to medicines for all SMA patients in the country. In addition to medication, therapy and adjunctive treatments are very important for SMA patients. I and we are working together to ensure these things. Besides, the work of all the members is divided individually. I am responsible for preparing statistics, taking care of patients and looking after legal matters of organization. I am currently giving importance to fulfilling the responsibilities assigned to me.

### 3. Focus.

We have developed a reliable database of SMA patients in Bangladesh. In order to create awareness about this disease, people from different levels of society are being included in related activities.

We have managed to form a care giver team consisting of 12 doctors to ensure medical facilities. We have formed an advisory committee to communicate this issue at the policy-making level of the government. Above all, we have created a medical guide so that patients can ensure some basic services themselves.

#### **4. Coming up**

Doctors in our country do not have much expertise in this treatment. Since we started working on the disease a few days back, we have not yet fully trained the related doctors. We want the cooperation of different countries in this regard.

Awareness about SMA disease is very low in Bangladesh. We are conducting various awareness raising activities through school-based campaign, online based campaign and through leaflets. We seek advice from experienced country representatives on how to do the job more effectively.