Subject : Request for the inclusion of Risdiplam in the WHO's Essential Medicine List (EML) for Spinal Muscular Atrophy (SMA)

Dear Sir/Madam,

I, [redacted] (mother of [redacted], who is a SMA patient) writing to request the inclusion of Risdiplam drug in the WHO's Essential Medicine List (EML). My 10-year-old son is suffering from Spinal Muscular Atrophy (SMA), a genetic disease that causes progressive muscle weakness and motor function loss. We have been struggling to provide our son with the best possible care, and the cost of the medication has been a significant financial burden on our family.

When Risdiplam was approved in India, we were overjoyed and even started a crowdfunding campaign to support the treatment. Unfortunately, we could only gather enough money for a few months, and we had to discontinue the medication due to its high cost.

During the months our son was on Risdiplam, we noticed significant improvements in his motor abilities. It was heartbreaking to discontinue the treatment, and we wish we could continue to provide our son with this life-changing medication.

We understand that adding Risdiplam to the WHO's EML could help parents like us who are forced to watch their children's slow deterioration. We believe that the inclusion of this drug in the EML will raise awareness of SMA and the importance of early diagnosis and treatment.

We urge you to consider adding Risdiplam to the WHO's Essential Medicine List, which will increase accessibility and affordability for SMA patients worldwide.

Thank you for considering our request and for your efforts to improve healthcare access globally.

Sincerely,

[redacted]
[redacted]