Respected Expert Committee Members,

Subject : Request to include Risdiplam (drug to treat SMA) in the WHO's essential medicine list (EML)
- [redacted] testimonial prepared by father

I am writing to draw your attention to the drug - Risdiplam , a treatment for genetic neuromuscular disease Spinal Muscular Atrophy, type 1 that my 2-year-old son is suffering from. We have been fortunate enough to purchase the drug Risdiplam from Roche Pharmaceuticals since 2021, which has proved to be highly beneficial for our son's condition.

Before taking this drug, my son had difficulty gripping our fingers and his muscle tone was very low. However, after starting the medication, we have noticed a significant improvement in his condition. He is now able to sit with support, and we have observed growth in his muscles.

As parents, our son is the hope of our life, and like every parent, we hoped that our child would be able to hold our finger as soon as he was born and provide support in our old age. With the help of this drug, we are seeing positive changes in his development and are hopeful for his future.

The cost of Risdiplam is INR 48 lakhs per year as per my son's current weight which is extremely high and unaffordable for our family. It is alarming to think about what could happen to our son without this medication when disease advances.

We strongly believe that including Risdiplam in the WHO list of essential medicines would provide much-needed access to this medication for all SMA patients, including our son. We earnestly appeal to you to consider our request urgently and add this drug to the essential medicine list as soon as possible. It would make a significant difference in the lives of countless families who are struggling to manage the high cost of this medication.

Thank you for your attention to this matter.

Sincerely,
[redacted]
Father of [redacted]