

Respected Sir/Madam,

My Son is suffering [REDACTED] 9 year old suffering from Spinal muscular atrophy (SMA Type 1) and is leading very painful life, every day is challenge for him, we have to do all his day to day activities(feeding , moving around, physio and others), he will be having frequent chest infection, Pneumonia episodes and hospitalisation, recently he had even Bradycardia and Cardiac arrest and he was on ventilator , by the God grace is back.

Even though there are medicines to treat SMA but affordability and accessibility is big challenge for us because of high price, In India Risdiplam is launched but we can't afford to buy medicine to treat my son, so he can live better life .

Kindly I request to include Risdiplam **Essential Medicines list** and if the price comes down, so at least we can give medicine and they can live better life , if the medicine is given early stage the results tremendous , show mercy on SMA kids and families who are leading painful life and include the medicine in **Essential Medicines list**.

Thank you.

Yours Faithfully,

[REDACTED]

(Father of SMA kid – [REDACTED])