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Title: Demand to make an affordable drug for spinal muscular atrophy, a rare disorder affecting mostly children in the country.

DR. DNV SENTHILKUMAR S. (DHARMAPURI): Vanakkam Speaker, Sir. I would like to bring to the notice of this House a rare disorder that affects mostly children. It is called muscular dystrophy. It is very rare that around 3,500 boys have been affected by this muscular dystrophy disease, and around 800 children have been affected by the spinal muscular atrophy. To cure this disease, medication or the gene mutation therapy should be given before two years of age or there is a greater possibility of losing the child.

The cost of the drug is around Rs.16 crore. The only way by which the parents can procure this drug is by private funding. Not all can do so, and even after achieving the target there is a GST of Rs.4 crore on this drug. Our Chief Minister, Thiru M.K. Stalin had written to the Finance Minister to waive off the GST of Rs.4 crore on this drug. It should not be done on case-specific basis. There should be a blanket ban of GST and the drug should be made available to everybody at an affordable cost.

As Article 21 ensures health for all, I would urge the Union Government, through you, Sir, to invoke compulsory licensing clause under Indian Patent Act drawing a parallel with TRIPS Agreement policy measures, taking route of trade margin rationalisation for capping the price to make the drug for SMA affordable to everybody in this country.

Thank you, Sir.