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Title: Regarding affordable medical treatment for Spinal Muscular Atrophy disorder -laid.

SHRI SYED IMTIAZ JALEEL (AURANGABAD): Spinal Muscular Atrophy (SMA) is a genetic disorder characterized by weakness and wasting Atrophy in muscles used for movement Skeletal muscles. It is caused by loss of specialized nerve cells. SMA mostly affects small babies and children at very early age. Babies with severe SMA type 1 do not live beyond to 1 or 2 years, Type 2 & 3 live up to teenage and adulthood. However, they are confined to wheelchair and go through Scoliosis of spine, poor lung functions about 625 patients exist in India. There are three life saving medicines approved for SMA by US FDA. However none of them are yet available in India.

However a reimbursement pathway would be needed for this.

I request the honourable minister to intervene to arrange access and affordability of treatment and cure for muscular Atrophy, Rare life threatening Neuro Muscular genetic Disorder &also make this medicine available in India so that all the SMA patients get a chance to live.