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Title: Regarding GST and Import charges waiver on medicines -laid.

**ADV. DEAN KURIAKOSE (IDUKKI):** The treatment of rare diseases such as, Gaucher disease, Pompe, MPS 1, Fabry, Spinal Muscular Atrophy are among the major rare diseases affecting our children, is an expensive affair and medicines are mostly Imported. Incapacity to afford the treatment, inadequate availability of medications, inaccessibility to advanced treatment facilities, are just a few of the problems the families face. Even though, such patients are quite a few in numbers, however, the treatment, modalities and research for such, result in exceedingly high cost to be borne by the patient. The average cost of such drugs starts around 43 lakhs annually for Gaucher disease and goes upto 18 crores for Spinal Muscular Atrophy. The overhead charges go upto more than 30-40% by the time they reach the patient hand.

Waiver of GST and Import charges on these medicines will be helpful, especially, towards people who are financially deprived. Hence, I humbly request your kind intervention.