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LSDSS appeals to PM for pledged Rs 100 Cr for treating rare diseases

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Letter of appeal submitted to Prime Minister’s Office, Ministry of Commerce and Industry, Ministry of Finance and Corporate Affairs, Ministry of Health and Family Welfare

Lysosomal Storage Disorders Support Society (LSDSS), a non-profit organization, representing the cause of patients and families affected by rare diseases, has appealed to the Hon’ble Prime Minister to save the lives of rare diseases patients, a majority of whom are children. LSDSS appealed the Prime Minister to release the pledged Rs. 100 crore for the treatment of rare diseases and immediately implement NPTRD, which had been withheld by the Government. The letter of appeal has been submitted to Prime Minister’s Office, Ministry of Commerce and Industry, Ministry of Finance and Corporate Affairs, Ministry of Health and Family Welfare.

For rare disease patients in India, the government’s promise to release Rs. 100 crores, under NPTRD, for the treatment of rare disease was the much-needed help for fighting these life-threatening diseases. However, the hope was shattered when in December 2018 Ministry of Health and Family Welfare announced that the policy is being “kept in abeyance.” This abrupt and surprising decision of the Government is a big setback for rare disease patients in India and has pushed their life towards uncertainty and death. Only Karnataka and Kerala state governments have come forward to help rare disease patients.

According to Manjit Singh, President, Lysosomal Storage Disorders Support Society (LSDSS): “We appeal to the Hon’ble Prime Minister for his urgent intervention in honouring the Government’s commitment towards rare disease patients in India. We request the Government to immediately revoke the ban on NPTRD and, as outlined in the policy, to immediately release the corpus fund with initial amount of Rs. 100 crore towards funding treatment of rare diseases. NPTRD is a progressive policy and its speedy implementation would ensure that treatment of rare diseases in India gets the much-needed boost that is immediately required.”

Under NPTRD the government has acknowledged the contribution of other countries in formulating patient-friendly policies and helping them access critical medical care. These countries include Chile, Peru, Argentina, Egypt, Thailand, Malaysia, Philippines and Serbia. A good example has also been set by governments of developed nations like Canada and Scotland with their own rare diseases policies that help patients in the treatment of rare diseases.

Lysosomal Storage Disorders Support Society (LSDSS) is headed by a group of parents of LSD Patients. The most common rare diseases recorded in India are Lysosomal Storage Disorders – Hunter Syndrome, Gaucher Disease and Fabry’s Disease. The diagnosis of LSDs unlike any other rare disorder is the first and most critical and frustrating challenge for anyone with a rare disorder. The Society represents and requests the Central and State Governments representatives for the immediate need of financial support and establishment of diagnostic facilities in all major hospitals of India for LSDs patients.