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Awareness and Help for rare Diseases

By Express News Service | Published: 04th March 2018 11:25 PM |

Last Updated: 05th March 2018 02:35 AM | [A+](#) [A](#) [A-](#) | 

KOCHI: In the backdrop of Rare Disease Day, Lysosomal Storage Disorders Support Society (LSDSS), a patient group association for Lysosomal Storage Disorders (LSDs) organised a rare disease awareness event in Kochi. The aim was to raise awareness about rare diseases, specifically LSDs, and its different aspects and to support the rare diseases community at large.

“Although rare, the number of patients suffering from such disorders is substantial considering the population of the country,” said Dr Vijaykumar, medical officer, Haemophilia Treatment Centre, Aluva. “It thus, becomes important that rare diseases get their due attention in the public health domain. Rare disease day is the perfect occasion to highlight the needs of patients and showcase how treatment can have a positive impact on a patient’s life.”

Commenting on the necessity of providing treatment, Dr Sheela Nampoothiri, clinical professor, Department of Pediatric Genetics, Amrita Institute of Medical Sciences & Research Centre, said, “The situation is more serious as the majority of the patients suffering from LSDs are children. Since the available treatment (Enzyme Replacement Therapy) is exorbitant, help will be required from the government.

In this regard, the National Policy for Treatment of Rare Diseases has already been finalised which has allocated Rs 100 crore corpus for rare diseases. The onus now lies on Kerala and other state governments to request a part of this corpus to be used for providing relief to rare disease patients without further delay.” LSD patients from Kochi, AIMS paediatrics head Dr Jayakumar and Hibi Eden MLA were present.

Rs100 cr corpus for rare diseases allocated in the National Policy for Treatment of Rare Diseases