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Over 50 Children from across state suffering from rare diseases gathered in city today to participate in a rare disease awareness program. The event was organized by the Lysosomal Storage Disorder Support Society (LSDSS). The aim was to create more awareness the public about among rare diseases and seek financial support from the government for the treatment of these debilitating genetic disorders.

The program witnessed a gathering of doctors and young children suffering from extremely rare type of genetic disorders such as Gaucher, MPS, Fabry and Pompe. The treatment of these very serious health conditions has become available with advancements in medical science, but is beyond the paying capacity of most patients. The hope for a better tomorrow triggered tremendous enthusiasm among the children at the event, as singer Shaan came forward to support and motivate the patients suffering from LSDs.

Patients suffering from Lysosomal storage Disorders (LSDs) are very few in number in India because of the rarity of these diseases. Dr Priya Kishnani, professor of Pediatrics, Division of Medical Genetics, Duke University said, " Patients suffering from Lysosomal storage Disorders (LSDs) are few in number (1 in 5000-7700) therefore their families have to face many hurdles in locating appropriate healthcare facilities and support centers that can provide them proper treatment and care. The treatment of some of these serious conditions has now become available with advancements in medical science but is beyond the paying capacity of most patients."

Lysosomal storage disorders (LSD) are a group of over 45 rare genetic disorders that occur due to the deficiency of specific enzymes in special compartments (lysosomes) of cells. LSDs occur in about one in 5,000 live births. A majority of LSDs are managed through supportive care measures that are disease-specific. However, six of the LSDs can now be treated through Enzyme Replacement Therapies (ERTs). India currently has about 300-400 patients who have been diagnosed with treatable LSDs.

Appealing to the state government of Maharashtra, Manjit Singh, president, Lysosomal Storage Disorders Support Society, said, "As treatment of these diseases is very expensive, it is beyond the reach of most of the LSD patients. Only government support can save these people and help them lead a better and close to normal life. The need of the hour is a government scheme to provide free treatment for patients with rare disorders. They are very few in number and it is the duty of the state to provide treatment for them."