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Delhi commemorates Rare Disease Day

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Lysosomal Storage Disorders Support Society (LSDSS) organised an event to spread awareness regarding rare diseases and its policy



On the occasion 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 Delhi.

The aim was to raise awareness about rare diseases, specifically LSDs, and its different aspects and to support the rare diseases community at large. The event was also a platform for applauding the national policy for rare diseases and to discuss the steps ahead to expedite the process of its implementation.

Lav Agarwal, Joint Secretary, MoH&FW who spearheaded the formulation and the finalization of the policy, Dr. Madhulika Kabra (Unit of Genetics, AIIMS), Dr. Seema Kapoor (Associate Professor, Department of Pediatrics, Maulana Azad Medical College) and patients in Delhi suffering from LSDs were present at the event.

Commenting on the event, Manjit Singh said, “Rare diseases, being uncommon, have seldom been considered as a major health issue. However, the commemoration of Rare Disease Day through events like these would ensure that rare diseases are given their due recognition. Moreover, our efforts have finally seen the light of the day with the finalization of the national rare disease policy which clearly showcases that the emphasis has been put on this healthcare challenge. Now its effective and swift implementation is crucial to ensure that the patients can avail its maximum benefit. Further, state being a health subject, it is important for the state government to take steps to draft its individual policy.”

Lav Agarwal said, “With the National Policy for Treatment of Rare Diseases being finalized, we are happy that our efforts have been acknowledged. There is a sort of satisfaction, although minimum, that the issue of rare diseases is now on the national front. The Rs. 100 crore fund is an element of hope and for the same we have proposed the formation of two committees- Technical and Administrative. These committees would initiate the process of identifying patients and providing them treatment. Moreover, to make the process less cumbersome, there would be a web-based application process where the patients can apply directly and from thereon it would be the responsibility of the centre and state governments to provide them treatment. The policy is a first step and it would be a matter of sometime before it gets implemented since it requires the coordination of all the concerned members and committees.”

Although rare, the number of patients suffering from such disorders is substantial considering the population of the country. This event being held on the occasion of rare disease day is the most appropriate way to highlight the various needs of the patients and also to showcase how treatment can have a positive impact on a patient’s life, especially in the case of LSDs.

Further elaborating, Dr. Seema Kapoor said, “The patients suffering from LSDs often lead chronic, debilitating lives and are not able to do even simple daily tasks. What is further disturbing is the fact that the majority of the patients suffering from LSDs are children. Certain concrete measures in the form of a strong rehabilitation and support treatment system along with the genetic counselling in high risk patients would be helpful in overcoming the diagnostic and treatment challenges.”

The event was also a platform for the patients to discuss their individual challenges and journey. It served as an opportunity for them wherein they were able to draw inspiration from each other’s struggles and positive stories.