

9th World Congress on

Rare Diseases and Orphan Drugs

June 17-18, 2019 | Berlin, Germany

Lysosomal storage disorders-updates from India

Shashank Tyagi

Lysosomal Storage Disorder Support Society, India

Lysosomal Storage Disorders Support Society a first, not-for-profit and pan India organization is registered and headquartered in New Delhi, India, headed by a group of parents and patients of LSD who know what it's like to live with Lysosomal Storage Disorders. LSDSS was formed formally in year 2010 to address the unmet needs and create awareness that benefit patients with lysosomal disorders in India. LSDSS works for creating awareness for prevention, timely and accurate diagnosis, consultation, symptomatic care and treatment options amongst patients, physicians, care givers and hospitals across India. LSDSS is a prime force behind the formation of National Rare Disease Policy in India by approaching the Judiciary through legal cases. LSDSS is doing advocacy in Government of India at Central and State level for better implementation of National Rare Disease policy. LSDSS has been organizing Rare Disease Day every year since 2010 and have been conducting Continuing Medical Education programs, Medical Camps, Media Workshops besides observing International Gaucher Day, MPS Day, Pompe Day, from time to time in association with major hospitals in different parts of India. Currently, LSDSS has 685+ treatable LSD afflicted registered patients from different parts of India and 35+ Specialized Medical Genetics doctor's and LSD Expert group from all over India working in tandem with emphasizing on need of accurate diagnostics facilities available and scouting for more avenues to get treatment options for unmet needs of hundreds other children's. LSDSS is also a member of many reputed International Groups working on rare disorders and won PAL award in year 2011.

SHASHANKTYAGI@LSDSS.ORG