

Lysosomal Storage Disorders Support Society

Northern Regional Off: 206, Top Floor, Duggal Complex, School Road,
Khan Pur, New Delhi-110062.

Ph: 011-30887492, Fax: 011-26829063,011-26847514

Mob No- 09810022645, 09829825533, 09899009057

Contact At: manjitsingh@lsdss.org

Registration N/ S/ 69555/2010 Under Societies Act 1860.

Donations to Society exempt U/S 80G of Income Tax Act Vide Registration
N.NQ.DIT(E)2012-13/DEL-LE23959-24052012/460, PAN N. AAATL8168J



LSDSS/2013/14/0002
12TH SEPTEMBER,2013
SH. MANMOHAN SINGH JI
PRIME MINISTER OF INDIA
SOUTH BLOCK,
NEW DELHI-110011

LSD(RARE GENETIC & FATAL DISEASES) SUFFERING
CHILDREN RENEW THEIR APPEAL TO CENTRAL
GOVERNMENT THROUGH HIGHEST OFFICE OF INDIA FOR
PROVISION OF TREATMENT TO THEM AS RIGHT TO
HEALTH
ON
SEPTEMBER IS WORLD LSD - GAUGHER AWARENESS
(RARE GENETIC DISORDERS) MONTH BEING
OBSERVED IN INDIA FOR 2ND TIME

REMINDER REMINDER REMINDER REMINDER REMINDER REMINDER
WHY NO ACTION . NO HEAD WAYS, NO MEETINGS WITH US NO HEARING
OUR CHIDREN ARE DYING FOR WANT OF MEDICINE
WE DONT NEED MONEY BUT TREATMENT THROUGH GOVT. HOSPITALS

Sub: Renewal of our Appeal on -Creation of Annual National Corpus of
Rs. 300 Crores IN Govt. Hospitals for management of Lysosomal Storage
Disorders (Rare Genetic & fatal Diseases) , early diagnosis facilities & Treatment
thereof. Refer our EARLIER REPRESENTATION DATED 26TH March,2013
submitted to your office on 2nd May,2013.

Hon'ble PRIME MINISTER SIR - Greetings from LSD Support Society!

It is our privilege to inform you that the patients, parents and caregivers of
Lysosomal Storage Disorders (LSDs) have come together to form a selfless & non
profit support group for the first time in India registered under Societies Act 1860.
We have identified & registered about 400 such Children who are suffering from
LSDs with our Society with help of Major Government Hospitals Medical Colleges
& Private Medical Institutions.

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Regd. Office: Centre for Genetic Medicine, GF,Sir Ganga Ram Hospital,Rajender Nagar,
New Delhi-110060

Registered under the Society Registration Act, 1860

Website: www.lsdss.org, E mail: manjitsingh@lsdss.org, umeshsharma@lsdss.org, rajendratyagi@lsdss.org

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LSDs are a group of approximately 45 rare genetic disorders that result from absence / malfunctioning of a specific enzyme in the human body. These are rare, progressive, debilitating and life-threatening diseases. Some of these diseases, namely Gaucher, Pompe, Fabry MPS-I, MPS-II and MPS-VI now have treatment options while some are expected to come in future.

While these therapies are life saving, they are too costly and prohibitive for us to afford. Making these therapies available through the Government channels is the only option for our afflicted children to survive and to live a near normal life. In the absence TREATMENT WE ARE LOOSING 5 TO 10 KIDS EVERY YEAR DUE TO THESE DREADED & KILLER DISORDERS. World over State governments are providing the medicine free to their citizens at state expense.

In India, every year, around 500 of the babies born every year are likely to be affected by treatable LSDs. The number actually diagnosed with a treatable LSD would be much lesser, as a significant proportion may not come to light owing to poor index of suspicion amongst our medical fraternity as well as poor diagnostic facilities. The estimate is that around 200-250 patients are currently diagnosed with treatable LSDs across the country annually.

We take this opportunity to request you to consider our plight and create a National Program for the Management of Lysosomal Storage Disorders. The fund would entail an yearly outlay of Rs 300 crores which would help diagnose, manage and treat our unfortunate children. Your decisive and immediate action can bring hope to all of us who, at present, have none just because we are very few in numbers and do not have a strong voice.

This fund will help the department of health to establish genetic diagnostic centers all over India in major Government Hospitals & medical colleges by equipping them with latest state of art hi definition Machines & instruments as well as arranging medicine – ERT for the suffering children & their symptomatic treatment reimbursement due to adverse & harm full prognosis of the the LSDs.

Your decision will create history in the advancement of health care scenario in India and would some day be considered as a life-changing milestone. We are enclosing a brief presentation on these disorders and objectives / activities of our Society.

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We would also request you to grant us an appointment so that we get an opportunity to present our case in person. Our Representation will consist of few office bearers, Head of Departments of Genetics of AIIMS Delhi , MAMC Delhi, Sanjay Gandhi Post Graduate Institute Of Medical Sciences & PGI Chandigarh. You can call them independently also if you wish so.

Thanking you in anticipation of a positive response.

For Lysosomal Storage Disorders Support Society (Regd.)


MANJIT SINGH
HON.PRESIDENT & Coordinator NCT of Delhi
PH: 09810022645, Fax 011-26829063, 26847154
Encl: Earlier Representation to Prime Minister,
Representation to Health Minister India &
:Appeal raised in Parliament

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