# A Small Act of Kindness: A New Lease On Life For Patients of Rare Diseases

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Lysosomal Storage Disorders Support Society v State of Karnataka, Writ Petition No. 19061 of 2015. This case highlights how the Karnataka High Court upheld free treatment for rare diseases Article 21 by directing government funding for patients suffering from Lysosomal Storage Disorders.

In an order that would assuage to some extent the misery of patients afflicted with life-threatening rare diseases, the Karnataka High Court has directed the State and the Centre to forthwith infuse Rs 6 crore into funds for free medical treatment of 45 such patients till June 2020.

A bench headed by the Chief Justice said so while hearing the plea of Lysosomal Storage Disorders Society of India (LSDSS), a pan Indian non-profit comprising patients of Lysosomal Storage Disorders (LSDs) and their relations, which was represented pro-bono by Team Anand and Anand.

The only two Pharmaceutical companies to manufacture medication for rare diseases have also undertaken to offer their otherwise highly unaffordable drugs at much lower rates to members of the petitioner Society.

Filed in year 2015, the petition had team ANA vehemently arguing that the fundamental Right of life and liberty granted to each and every person by the Constitution of India covers free medical treatment for patients of rare diseases.

The Karnataka High Court order had a domino effect as it led to high courts in many states passing similar orders. In one such case before the Madras High Court, the bench relied heavily on the order passed by the Karnataka High Court in our case and asked the State and the Centre to shun their perception that these diseases cannot be permanently cured as "one should not forget that hope itself, at times, brings about miracles".

While nudging the governments to stay hopeful, the Madras High Court directed Tamil Nadu to immediately allocate at least Rs 5 crore to meet any immediate or urgent medical expenses of such patients. At the same time, it directed the Centre to provide for the one time aid in respect of at least 11 patients to the tune of Rs. 4,40,00,000, as an interim measure since the annual expenditure for the meeting of medicinal treatment of such patients is approximately Rs. 40 lakhs per head.

Relying heavily on the Karnataka High Court order and another order from the Kerala High Court, the Madras HC said, "We find that keeping in view the fact that a right to survival is recognised as a part of Article 21 of the Constitution of India in the background aforesaid, the aforesaid two High Courts have also pioneered in proceeding to make provisions for funds in order to ensure the

availability of treatments to patients suffering from rare diseases, which are usually terminal in nature. "It is to be noted that LSDs are internationally recognized as rare diseases owing to the rare nature of prevalence. Their occurrence is attributed to defects in lysosomal functions and mostly affect children resulting in their unfortunate death at a young and unpredictable age.

LSDs comprise approximately 40 disorders such as Gaucher, Pompe, Fabry MPS Type I(Hurler Syndrome), MPS Type II (Hunter Syndrome), MPS Type IV (Morquio Syndrome)amongst others. Only a few of these LSDs can be medically treated through Enzyme Replacement Therapy (ERT), while symptomatic treatment is administered for remainder of the disorders. LSDs for which ERTs are available affect around 1 in 40,000 to 1 in 400,000 children. Due to its astronomical costs, ERT remains beyond reach for most patients.

In 2014-15, the state of Karnataka had announced fund allocation for treatment of rare diseases while also announcing a special unit at the Indira Gandhi Institute for Child Health for administration of such treatment. It, however, was nothing more than lip service and children afflicted with rare diseases continued to suffer severe health degradation. When several political, bureaucratic, and social initiatives failed to swing government in action, LSDSS moved court and entrusted ANA with the responsibility of securing free treatment for those suffering. We consistently argued that no amount of financial constraints of the State could allow it to derogate from its duty to provide for the needy while also ensuring the Centre shoulders the responsibility.

This order has granted a much-needed lifeline to patients and young children, whose lives can no longer be held ransom to government red tapism and political delays.

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