



Karnataka High Court confirms free treatment for children suffering from LSDs

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Lysosomal Storage Disorders (LSDs) are rare hereditary disorders which usually afflict children, proving fatal within a few years of birth. The necessary treatment, Enzyme Replacement Therapy, is prohibitively expensive and beyond the means of even the wealthier sections of society. The State government of Karnataka allocated funds in its 2014 budget for the treatment of rare diseases, identifying the Indira Gandhi Institute of Child Health (IGICH) as the concerned medical authority to absorb such funds and provide necessary treatment. IGICH did not commence treatment of children suffering from LSDs. Repeated requests and campaigns by the Petitioner (a society whose members comprise children suffering from LSDs, their parents and guardians) did not result in provision of funds for the facilitation of treatment. In the wake of young children succumbing to the disease and being unable to avail the necessary treatment, the Petitioner moved Karnataka High Court at Bangalore. On the very first day of hearing the High Court directed IGICH to provide for medical treatment, free of cost, to children suffering from LSDs. The order went unheeded, Respondents not facilitating treatment free-of-charge, citing unavailability of requisite funds. Taking exception to the situation after contempt petitions and repeated applications were filed before it, the court has issued a blanket direction to the Respondents to ensure that treatment is provided free of cost to children suffering from LSDs. Though the Respondents cited budgetary constraints once again, the court disregarded the same, stating that monetary issues could be discussed at later stages as well. The court's message is clear: official authorities must be accountable for public health issues especially where a commitment has been made for facilitation of treatment. *Lysosomal Storage Disorder Society of India v. State of Karnataka*



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