

**IN THE HIGH COURT OF PUNJAB AND HARYANA  
AT CHANDIGARH**

**117**

**CWP-6557-2025**

**Date of Decision : March 24, 2025**

**MASTER SAMARBIR SINGH THROUGH HIS GUARDIAN**

**-PETITIONER**

**V/S**

**UNION OF INDIA AND OTHERS**

**-RESPONDENTS**

**CORAM: HON'BLE MR. JUSTICE KULDEEP TIWARI**

Present: Mr. Abhishek Batta, Advocate and  
Mr. Ankush Thakral, Advocate  
for the petitioner.

Mr. Satya Pal Jain, Addl. Solicitor General of India, with  
Mr. Rajiv Sharma (Hisarwale), Advocate  
for the respondents No.1 and 3 to 5.

Mr. Pardeep Bajaj, D.A.G., Punjab  
for the respondent No.2.

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**KULDEEP TIWARI, J. (ORAL)**

1. Unfortunately, the petitioner, who is aged about 08 years, has been diagnosed with Duchenne Muscular Dystrophy, which is a rare and severe genetic disorder. Therefore, by instituting the instant writ petition through his legal guardian, the petitioner prays for issuance of directions upon the respondents No.4 and 5 to ensure purveying medical treatment to him under the National Policy for Rare Diseases, 2021, and, as per the judgment rendered by the Delhi High Court in *“Master Arnesh Shaw Vs. Union of India and Anr.”*, W.P. (C) 5315/2020.

2. Consequent upon this Court issuing notice on the instant writ petition on 10.03.2025, the learned Additional Solicitor General sought some

time to have apt instructions from the quarter concerned regarding grievance of the petitioner. Accordingly, today the learned Additional Solicitor General has filed the reply dated 23.03.2025, which is taken on record.

3. The reply makes revelations that, the petitioner was examined by the Department of Pediatrics (Neurology Unit) and he has been diagnosed with Duchenne Muscular Dystrophy. The duly filled application of the petitioner for financial assistance under the National Policy for Rares Diseases has also been submitted to the Institute Rare Diseases Committee.

4. What further surges forth from the reply is that, the maximum cumulative assistance under the National Policy for Rare Diseases is ₹ 50 lacs and this amount is sufficient for providing medicines to the petitioner only for two months. Therefore, for opting this financial assistance of ₹ 50 lacs, the written consent of the petitioner's legal guardian/parents, in the prescribed proforma, is required.

5. The learned counsel for the petitioner submits that, although as per the judgment (supra) rendered by the Delhi High Court, there is no maximum cap, which can be imposed on grant of financial assistance for treatment of rare diseases, however, since the legality of the judgment (supra) is under legal scrutiny by Hon'ble the Supreme Court and the operation thereof has also been, subject to the Union of India complying with the apposite notification and also issued directions for payment on a case to case basis, whenever it is required, stayed by Hon'ble the Supreme Court through drawing the order dated 09.12.2024 upon SLP (C) No.28777/2024, therefore, at this stage, the petitioner's legal guardian/parents may be allowed to furnish the requisite consent, but, subject to the outcome of the SLP (supra).

6. The prayer made by the learned counsel for the petitioner is not

opposed by the learned Additional Solicitor General.

7. In view of the above, especially the fact that the petitioner requires immediate medical care and medicines, this Court deems it appropriate to **dispose of** the instant writ petition with a direction upon the respondent(s) concerned to, as and when the petitioner’s legal guardian/parents furnishes the written consent, forthwith release the requisite funds required for medical care and medicines of the patient periodically. Moreover, the petitioner is also at liberty to claim any other apposite/additional relief(s), by approaching the competent authority/forum.

8. **Disposed of accordingly.**

March 24, 2025  
devinder

(KULDEEP TIWARI)  
JUDGE

|                           |   |        |
|---------------------------|---|--------|
| Whether speaking/reasoned | : | Yes/No |
| Whether Reportable        | : | Yes/No |