

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

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CWP-1658-2025 (O&M)

Date of Decision : March 17, 2025

VIKRAMJEET SINGH

-PETITIONER

V/S

UNION OF INDIA AND OTHERS

-RESPONDENTS

CORAM: HON'BLE MR. JUSTICE KULDEEP TIWARI

Present: Mr. Chahit Bansal, Advocate
for the petitioner.

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

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

KULDEEP TIWARI, J. (ORAL)

CM-3689-CWP-2025

1. For the good and valid reasons, as assigned in the instant preponement application, the application is **allowed**. The main case is ordered to be taken on board today itself for hearing.

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2. Unfortunately, the petitioner's son (hereinafter referred to as the 'patient'), who is aged approx. 1½ years, has been diagnosed with Spinal Muscular Atrophy (SMA) Type-I, which is a rare and severe genetic disorder, therefore, through instituting the instant writ petition, the petitioner prays for issuance of directions upon the respondents No.4 and 5 to ensure purveying medical treatment to the patient 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.

3. This Court had, at the time of issuing notice upon the instant writ petition on 22.01.2025, directed the petitioner to, along with the patient, appear before the P.G.I.M.E.R., Chandigarh, thereby enabling the latter to evaluate the medical status of the patient and to make recommendation to the National Rare Diseases Cell.

4. In pursuance to the directions (supra), the petitioner along with the patient appeared before the concerned department of the P.G.I.M.E.R., Chandigarh, for medical examination. After medical assessment of the patient, the learned senior counsel for the respondents No.1 and 3 to 5 furnished the reply dated 09.02.2025 before this Court. The reply made revelations that, the patient was examined by the Department of Pediatrics (Neurology Unit) and he has been diagnosed with Spinal Muscular Atrophy (SMA) Type-I. The diagnosis has been confirmed with SNM1 Gene Analysis. MLPA (Multiplex Ligation-dependent Probe Amplification) for SNM1 Gene showed presence of homozygous deletion of exon 7 and 8. Hence, the patient has been advised to continue multidisciplinary supportive care. Moreover, he has been advised risdiplam as a disease modifying therapy for underlying disease process. Also, the duly filled application of the patient for financial assistance under the National Policy for Rare Diseases for RISDIPLAM has also been submitted to the Institute Rare Diseases Committee.

5. What further surges forth from the reply (supra) is that, the maximum cumulative assistance under the National Policy for Rare Diseases is ₹ 50 lacs and this amount is sufficient for providing medicines only for two years. Therefore, for opting this financial assistance of ₹ 50 lacs, the written consent of the petitioner, in the prescribed proforma, is required.

6. 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 may be allowed to furnish the requisite consent, but, subject to the outcome of the SLP (supra).

7. The prayer made by the learned counsel for the petitioner is not opposed by the learned senior counsel for the respondents No.1 and 3 to 5.

8. In view of the above, especially the fact that the patient 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 furnishes his 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 relief(s), by approaching the competent authority/forum.

9. **Disposed of accordingly.**

March 17, 2025
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(KULDEEP TIWARI)
JUDGE

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