

24.04.2025
Item Nos.26-28
gd/ssd

WPA(P)/20/2020
CAN/1/2023, CAN/2/2023
MUSCULAR DYSTROPHY PATIENT
WELFARE SOCIETY & ANR.
VS
MINISTRY OF HEALTH & FAMILY WELFARE,
GOVERNMENT OF INDIA & ORS.
with
WPA/6300/2023
YUVAAN SINGH & ORS.
VS
UNION OF INDIA & ORS.
with
WPA(P)/9/2023
PARIVAAR BENGAL & ANR.
VS
STATE OF WEST BENGAL & ORS.

Ms. Nandini Mitra,
Mr. Samim Ahammed,
Ms. Saloni Bhattacharya,
Ms. Gulsanwara Pervin,
Mr. Arka Ranjan Bhattacharya,
Ms. Ambiya Khatoun
..for the Petitioners in
WPA(P) 20 of 2020.

Mr. Siddhartha Sankar Mandal,
Ms. Arunima Das Sharma
..for the Petitioners in
WPA 6300 of 2023.

Mr. Kaushik Gupta,
Ms. Srimoyee Mukherjee
..for the Petitioners in
WPA(P) 9 of 2023.

Mr. Asok Kumar Chakraborti,
Id. Additional Solicitor General,
Mr. Tirtha Pati Acharya,
Mr. Arijit Majumdar
..for the Union of India in
WPA(P) 20 of 2020 and
WPA 6300 of 2023.

Mr. Suman Chattopadhyay
..for the Union of India in
WPA(P) 9 of 2023.

Mr. N. Chatterjee,
Mr. S. Adak

..for the State in
WPA(P) 20 of 2020 and
WPA(P) 9 of 2023.

Mr. Tapan Kumar Mukherjee,
Mr. Somnath Naskar

..for the State in
WPA 6300 of 2023.

1. Reference may be made to the order dated 19.09.2024. There was several aspects to the said order and the first aspect is the payment of Rs.1,000/- to the persons suffering from rare diseases which is being presently paid by the West Bengal and the court expressed an opinion that it is inadequate. In this regard, instructions were required to be obtained which has not been placed before this court today. On the next hearing date the relevant instruction should be placed in terms of the directions issued in paragraph 5 of the order dated 19.09.2024. The next aspect is with regard to the directions issued by the Hon'ble Supreme Court with regard to the supply of certain medicines etc.

2. The learned Central Government standing counsel has produced the written instruction given to him by the Under Secretary to the Government of India, Ministry of Health and Family Welfare, Department of Health and Family Welfare (Rare Disease Cell) dated 18th October, 2024.

3. In the said written instruction it has been stated that a sum of Rs.10 Crores was sanctioned and paid to the IPGMER, Kolkata vide Sanction Order dated 24.5.2024.

4. The respondent/State shall file a report as to how this amount has been utilized.

5. We have taken note of the order passed by the Hon'ble Delhi High Court which had issued various directions and as against the said order dated 4.10.2024 in WP(C) 5315 of 2020 the Union of India had filed an appeal before the Hon'ble Supreme Court in Special Leave to Appeal (C) No.28777 of 2024 and the Hon'ble Supreme Court has granted an order of stay except the compliance of the notification issued by the Union of India dated 19.5.2022. The said notification deals with financial support for treatment of people suffering from rare diseases and the financial assistance has been increased upto Rs.50 lakhs.

6. The appropriate authority of the Central Government shall file a report as to whether this increased amount has been paid to the IPGMER, Kolkata in terms of the said notification.

7. It is unfortunate that in spite of the direction issued by this court earlier not only to provide ramps in the hospital and also to provide mechanised wheel chairs, the State has been insensitive to the same and has not been complied with.

8. However, Mr. Mukherjee, learned senior counsel appearing for the State assures the court by the next hearing date it will be complied with. The State shall ensure that mechanised wheel chairs not less than five are provided to the hospital within seven days from date, otherwise the court may be constrained to initiate suo motu action for contempt.

9. On the next date the State Government shall also respond as to why a three-bed ICU unit should not be directed to be established in the police hospital exclusively for urgent cases of patients suffering from rare diseases.

10. List these matters on 15th May, 2025.

(T. S. SIVAGNANAM)
CHIEF JUSTICE

(CHAITALI CHATTERJEE (DAS), J.)