

23.05.2025
Item Nos.1-3
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,
..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. Ashoke 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.

Md. T.M. Siddique,
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. We have heard the learned advocates for either of the parties.

2. By order dated 24.4.2025 four issues were pointed out, namely, (1) as to how Rs.10 Crore sanctioned and paid to IPGMER, Kolkata has been utilized.

3. The learned senior advocate appearing for the State submitted that his officer has prepared a report and the utilization certificate will also be placed before this court will also be placed before this court and copy of which has been handed over to learned advocate for the petitioners who is entitled to respond to such note/certificate.

4. The next aspect is with regard to the enhancement of stipend of Rs.1,000/- paid to the patients of rare disease.

5. The response of the State is that all persons with disabilities have been paid a monthly stipend of Rs.1,000/- and the same has been extended to persons suffering from rare diseases.

6. So far as persons suffering from rare diseases are concerned, they cannot be equated to person who is normally classified as a person with disability though the person suffering from rare diseases is undoubtedly a person of rare disability, however, the disability is more severe as it is a degenerative disease.

7. Therefore, the persons suffering from rare diseases should be treated as a class of themselves and a stipend of Rs.1,000/- should be increased as this will be wholly inadequate.

8. The court would suggest the stipend of Rs.5,000/- per person suffering from rare diseases.

9. In this regard, the appropriate authority of the State Government is at liberty to respond by filing a report in the form of an affidavit.

10. The other direction issued was with regard to providing five mechanized wheel chairs and the same was required to be procured within seven days.

11. This direction has not been complied with that it is submitted by the learned advocate for the State that tenders have been called for three mechanized wheel chairs.

12. It is not clear as to why the authority should resort to a tender process for procuring five mechanized wheel chairs as undoubtedly the tender process is time consuming. Providing wheel chairs is a basic necessity more particularly mechanized wheel chairs considering

the condition of the patients suffering from rare diseases.

13. Therefore, the appropriate authority of the State Government shall take expeditious decision and ensure that the five mechanized wheel chairs are procured and supplied to the hospital not later than 13th June, 2025.

14. The next aspect which was pointed out is that as to why the three bed ICU unit should not be established in the police hospital.

15. The Head of the Department, Department of Neonatology and Nodal Officer, COE of Rare Disease, IPGME&R, SSKM Hospital, Kolkata along with Professor and Head of the Department, Department of Pediatric Surgery and Chairman, COE of Rare Disease, IPGME&R, Kolkata have filed a report.

16. Among other things the following has been stated with regard to the indoor admission facility:

“Indoor admission facilities:

- a) Eight beds for male and female patients with rare diseases are kept reserved at the indoor ward of KPH for rare disease cases including muscular dystrophy. Five beds are equipped with life support systems, one such bed is placed at day care centre for children to manage any adverse reaction during infusion of drugs for rare diseases.
- b) Being the annex to IPGME&R SSKM hospital the emergency of KPH is merged with that of SSKM hospital main campus. Any rare disease patient attending SSKM hospital for emergency will be initially evaluated at SSKM hospital and after initial stabilization he or she

will be admitted at SSKM hospital ward, CCU, neurology ICU, Ramrik hospital ICU (IPGME&R SSKM hospital annex) or at KPH indoor rare disease beds as priority basis. The admission in the respective wards of SSKM hospital main campus or at the various annex hospitals will be subject to the availability of beds.

- c) The 24 hours on duty doctors at indoor ward of KPH will be managing rare disease cases.
- d) The pediatric muscular dystrophy cases will be admitted at Pediatric ward or PICU of SSKM hospital as per requirement.”

17. It is no doubt true that adequate facility has been provided in the SSKM hospital which is stated to be in the same campus where the police hospital is situated.

18. However, in terms of Para (b) of the above report, the admission of the patients will be subject to availability of beds.

19. The court can take judicial notice of the fact that there is overcrowding in the hospitals and very often beds are not available.

20. Therefore, this court suggests that a three bed ICU unit could be established in the police hospital exclusively care to the persons suffering from rare diseases, apart from the facility available in the SSKM hospital and the other hospitals which are situated in and around the police hospital.

21. This issue may be addressed adequately and a report be submitted on the next hearing date.

22. We record our appreciation to Prof. (Dr.) Suchandra Mukherjee, Head of the Department, Department of Neonatology, Nodal Officer, COE of Rare Disease, IPGME&R, SSKM Hospital, Kolkata who is personally present before us and explained the various procedures.

23. We have suggested that the tablet “Deflazecort” which is the approved therapy for DMD be given to the patients to cover the dosage for minimum two months. If the tablets which are dispensed are for lesser period, then each time the patient needs to travel to the hospital which is a herculean task for persons suffering from rare disease.

24. Therefore, it is our suggestion that the drug can be dispensed to cover the dosage for a minimum of two months. After the expiry of two months, the concerned patient shall come to the hospital for evaluation and upon evaluation the drug can be dispensed for a further period of two months.

25. In the preceding paragraph we have stated about the need to establish at least a minimum three bed ICU in the police hospital.

26. This is so required because high speed oxygen is required for the patients and in the event there is no bed available in the SSKM hospital main campus, then the patient will be put to irreparable hardship.

27. One of the parents of the patients in court who happens to be an employee of the High Court and he is stated that his son recently became very sick and since no ICU bed was available, he had to admit his son to a private hospital and was kept in the ICU for ten days and the cost incurred was very high and unmanageable.

28. Therefore, suggestion which is fallen from this court may be considered by the authorities.

29. By order dated 17.4.2023 we have requested the learned Additional Solicitor General to provide necessary information whether other Centres of Excellence in addition to the present located in Kolkata can be established in other parts of the State of West Bengal.

30. Response was given and we are informed that very recently a Centre of Excellence has been opened in Imphal, Manipur State.

31. The learned Additional Solicitor General is requested to examine the policy frame by the Central Government with regard to establishment of Centres of Excellence more than one Centre of Excellence in a State and assist the court as to what directions can be issued so that another Centre of Excellence can be established in the State of West Bengal since the court is informed that not only patients from West Bengal come to the Centre of Excellence but also from the

neighbouring State such as Odisha, Jharkhand, Bihar, Sikkim etc.

32. In the report to be filed by the appropriate authority of the State Government, the number of persons suffering from rare disease as per the records maintained by the hospital shall be made known in the said report.

33. Another suggestion which has fallen from the learned advocate for the petitioners is that the persons suffering from rare disease would require the assistance of a mechanized wheel chair which will enable them to move around within the house or in their locality.

34. The court suggests that the appropriate authority of the State Government may consider whether a subsidy can be given for the purchase of mechanized wheel chair and the cost to be initially borne by the parents or the persons suffering from rare disease and upon production of the payment invoice subsidy can be released.

35. This aspect shall also be covered in the report which has been directed to be submitted.

36. The utilization certificate dated 30th April, 2025 has been submitted which is taken on record and a copy of the said certificate be furnished to the learned advocate appearing for the writ petitioners.

37. Liberty is granted to the petitioners to file report.

38. List these matters on 27th June, 2025.025-+

(T. S. SIVAGNANAM)
CHIEF JUSTICE

(CHAITALI CHATTERJEE (DAS), J.)