

01.07.2025
Item Nos.1 to 3
PG/KS
Ct. No.1

W.P.A.(P) 20 of 2020
With
IA No. CAN 1 of 2023
+
CAN 2 of 2023
Muscular Dystrophy Patient Welfare Society & Anr.
-Vs.-
Ministry of Health & Family Welfare
Government of India & Ors.

With
W.P.A. 6300 of 2023
Yuvaan Singh & Ors.
-Vs.-
Union of India & Ors.
With
W.P.A.(P) 9 of 2023
Parivaar Bengal & Anr.
-Vs.-
State of West Bengal & Ors.

Ms. Nandini Mitra
Ms. Saloni Bhattacharyya
Ms. Gulsanwara Pervin

.....For the Petitioners
in
(W.P.A.(P) 20 of 2020)

Mr. Biswaroop Bhattacharya
Mr. Sidhdhatha Sankar Mandal
Ms. Arunima Das Sharma

.....For the Petitioners
in
(W.P.A. 6300 of 2023)

Mr. Kaushik Gupta
Ms. Srimoyee Mukherjee

.....For the Petitioners
in
(W.P.A.(P) 9 of 2023)

Mr. Asok Kumar Chakraborti, Ld. A.S.G.
Mr. Arijit Majumder
Mr. Tirthapati Acharya

.....For the U.O.I.
in
W.P.A.(P) 20 of 2020) &
W.P.A. 6300 of 2023

Mr. T. M. Siddique
 Mr. Suddhadev Adak
 Mr. T. Chakraborty
 Ms. Richa Pramanik

.....For the State
 in
 (W.P.A.(P) 20 of 2020)

Mr. T. M. Siddique, Sr. Adv.
 Mr. Nilotpal Chatterjee
 Mr. S. Adak

.....For the State
 in
 & (W.P.A.(P) 9 of 2023)

Mr. Tapan Kumar Mukherjee, Sr. Adv.
 Mr. Somnath Naskar

.....For the State
 in
 (W.P.A. 6300 of 2023)

1. Reference may be made to the order dated 23rd May, 2025 in which several issues were pointed out and highlighted and certain directions were issued. The first of such direction was to consider providing a stipend of Rs.5,000/- per person suffering from rare diseases and the appropriate authority of the State Government was granted liberty to respond to this suggestion by the Court by filing a report in the form of an affidavit.
2. The learned senior advocate appearing for the State on instruction submitted that the issue is being deliberated at the highest level and seeks for reasonable time to file a report in the form of an

affidavit. Such submission is placed on record and the said report in the form of an affidavit be filed on the next hearing date.

3. The next direction was to provide five mechanised wheel chairs in the hospital. This direction has been complied with and in proof thereof, the report of installation, as prepared by the General Manager, West Bengal Medical Services Corporation Limited dated 10th June, 2025 has been placed. The same is taken on record and the said issue stands addressed.
4. The third aspect is with regard to providing the tablet 'Deflazecort' for a minimum period of two months. To the said effect, an order has been passed by the Medical Superintendent-cum-Vice-Principal, IPGME&R – SSKM Hospital, Kolkata, Centre of Excellence dated 27th May, 2025.
5. The learned advocate appearing for the petitioners would submit that alongwith the aforementioned drugs, there are other drugs, which are required to be taken by the persons suffering from Muscular Dystrophy as they often suffer from other symptoms on account of being administered with steroids. The Medical Specialist shall consider this

aspect as well and in addition to the 'Deflazecort' tablet, such medicines, which are required to handle the symptoms as well as for improving health of the patients may also be provided for a minimum period of two months.

6. The next aspect is providing an exclusive ICU Unit for the persons suffering from very rare diseases.
7. It is submitted by the learned advocate appearing for the petitioners that "rare disease" is a very broad classification and exclusive ICU beds may be reserved for persons suffering from Muscular Dystrophy. Two proposals have been given of which we find the proposal of setting up a three-bedded ICU Unit in the ground floor at Kolkata Police Hospital to be more effective to address to the need. Since, there are various categories, which fall under the broad classification of "rare disease", we would recommend a five-bedded ICU Unit to be provided at the ground floor at Kolkata Police Hospital of which three beds can be reserved for patients suffering from Muscular Dystrophy and the remaining two ICU beds for the persons suffering from other rare diseases.

8. The appropriate authority of the State Government is directed to consider this suggestion and it will be well-appreciated if the same is accepted.
9. It is submitted that the persons suffering from Muscular Dystrophy have to be assessed for their sleeping pattern and therefore, a sleep study test is required, which can be conducted by using appropriate equipment. The concerned authority of the State Government shall also respond as to whether such equipment for the purpose of conducting sleep study test can be installed in the Kolkata Police Hospital alongwith Bipap Machine. This aspect shall also be addressed in the report, which shall be filed by the appropriate authority of the State Government.
10. By an earlier order dated 17th April, 2023, the learned Additional Solicitor General was requested 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. In this regard, a response has been given 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 17th June, 2025 addressed to the learned Additional Solicitor General. From the said communication, it is seen that as per the data furnished by IPGMER, Kolkata 770 rare disease patients have been registered at the institute over the last five years and given this patient load, it is not considered feasible to designate more than one Centre of Excellence in the State of West Bengal, at this stage. Furthermore, the communication states that the request for consideration of Centre of Excellence in the States of Jharkhand, Orissa, Assam and Bihar is under evaluation for their potential recognition as Centres of Excellence in accordance with the standard criteria. Therefore, for the present, it may not be feasible for considering the request for opening one more Centre of Excellence in the State of West Bengal, more particularly, when there are only 13 Centres of Excellence in the country and some of the States do not have the said facility. The communication sent by the Government of India addressed to the learned Additional Solicitor

General dated 17th June, 2025 is taken on record and the issue stands closed.

11. In the earlier order, a suggestion was made to the State Government to consider whether subsidy can be given for the purchase of mechanised wheel chairs and the initial cost will be borne by the parents of the persons suffering from rare disease, in particular Muscular Dystrophy. It is submitted by the learned advocate appearing for the petitioners that there is a company, which supplies light-weight foldable wheel chairs at very affordable price.
12. We direct the parent of one of the child suffering from Muscular Dystrophy to obtain a proforma invoice from the said company to assess the financial outlay that may be required to be provided by the State Government for purchasing the said wheel chairs. Let such proforma invoice be placed before this Court on the next hearing date.
13. The next aspect, which has been highlighted before us is that persons suffering from Muscular Dystrophy may require other devices such as Afo Night Splint Legs, Knee Orthosis, Braces/Belts for

spine and we are informed that these items are supplied free of cost by the National Institute For Locomotor Disabilities, which is located at Bonhooghly. We request the learned Additional Solicitor General to obtain appropriate written instruction from the Director of the said National Institute as to whether these items could be supplied to the persons suffering from Muscular Dystrophy upon due certification by the concerned hospital free of cost.

14. It is brought to the notice of this Court that these items are required for persons, who are in the early stage of Muscular Dystrophy and who are not wheel chair bound. Let the Director of the National Institute For Locomotor Disabilities give appropriate written instruction to the learned Additional Solicitor General in this regard.

15. One more aspect, which has been highlighted is with regard to the disability certificate, which has been issued in particular, the percentage of disability. One of the parents of child suffering from Muscular Dystrophy is present in Court and it is submitted that he had filed an application for

issuance of a certificate in the Portal in the year 2020 and certificate was issued in the year 2025 certifying that his son is 70% disabled. However, the appropriate Board, which examined him as on date, has certified that he is suffering more than 90% disability. This aspect of the matter has to be taken note of by the appropriate authority since Muscular Dystrophy is a progressive disease and, therefore, the percentage of disability is bound to increase.

16. Therefore, the learned Additional Solicitor General is requested to get appropriate instruction as to how the percentage of disability as and when it increases can be uploaded in the Portal and the procedure to be adopted in this regard may be furnished preferably in a flow-chart format.
17. It is made clear that such amendment of the percentage of disability can happen only after the appropriate Medical Board certifies the patient, who suffer a particular percentage of disability and based on such certification, the information available in the Portal has to be amended. The appropriate authority of the Government of India

may give necessary written instruction to the learned Additional Solicitor General in this regard.

18. One more suggestion, which has fallen from the parents of the children suffering from Muscular Dystrophy is to keep the Out Patient Department (O.P.D.) open in the Hospital for treating patients with rare diseases on two days in a week instead of one day as is presently being done as the pressure on the Medical Faculty is also more on that particular day. This aspect may also be considered by the appropriate authority of the State Government and a report in this regard shall be filed.

19. By our earlier order dated 9th May, 2024, this Court directed the Registry to send notices to the various Chambers of Commerce requesting them to give their views and suggestions as to whether the Members, who are Corporate Houses are willing to contribute their CSR exclusively for treatment of the patients suffering from rare diseases in the State of West Bengal. The relevant portion of the said order dated 9th May, 2024 is quoted hereinbelow:-

“14. The court took note of the suggestion that various Chambers of Commerce are actively carrying on

activities in the State of West Bengal and if they are put on notice, their views and suggestions can be invited as to whether their Members who are Corporate Houses in the State of West Bengal can consider and donate a portion of the CSR exclusively for treatment of the patients suffering from rare diseases in the State of West Bengal.

15. The learned advocate for the petitioners has given a list of Chambers of Commerce who are carrying on their activities in the State of West Bengal in order to invite them to give their views and suggestions. We deem it appropriate that notices can be sent to all the Chambers of Commerce, namely, (1) The Bengal Chamber of Commerce and Industry, Royal Exchange Building, 6, Netali Subhas Road, Murgighata, B.B.D. Bagh, Kolkata, West Bengal 700001, 033 22303733; (2) Calcutta Chamber of Commerce, Stephen Court, 18-H, Mother Teresa Sarani, Park Street Area, Kolkata, West Bengal 700071, 033 2229 0758; (3) Indian Chamber of Commerce, ICC Towers, 4, India Exchange Pl Rd, Murgighata, B.B.D. Bagh, Kolkata, West Bengal 700001, 033 2253 4200; (4) Bharat Chamber of Commerce, 7 Point, 9/1, Syed Amir Ali Ave, beside Zeeshan Restaurant, Park Circus, Ballygunge, Kolkata, West Bengal 700017, 033 2282 9591; (5) Merchants' Chamber of Commerce & Industry (MCCI) 2nd floor, Octavius Chamber, 15-B, Hemanta Basu Sarani, Kolkata, West Bengal 700001; and (6) Bengal National Chamber of Commerce & Industry, 23, RN Mukherjee Rd, Esplanade, Lal Bazar, Kolkata, West Bengal 700001, 033 2248 2951.

16. The Registry is directed to send notices to all the abovementioned Chambers of Commerce informing them that the court requests them to give their views and suggestions as to whether their Members who are Corporate Houses are willing to contribute a portion of their CSR exclusively for treatment of the patients suffering from rare diseases in the State of West Bengal.

17. Upon notice being served and after hearing the respective Chambers of Commerce, the court will take further decision in these matters."

20. The Court has been informed that notices have been served. This is evident from the report submitted by the Section Officer, Central Despatch Section.

However, none of the Chambers of Commerce has responded. We would request the learned advocates appearing for the petitioners to inform the counsels, who are associated with the Chambers of Commerce or who are advising Corporate Houses, who, obviously would be Members of the Chambers of Commerce to extend a helping hand to the persons, who are suffering from rare disease.

21. During the course of hearing, Mr. Shiv Shankar Banerjee, learned advocate (Mobile No.9830213870) has expressed his desire to sponsor five wheel chairs. The said submission is placed on record and will be taken into consideration when orders and directions are issued in this regard.
22. Mr. Biswaroop Bhattacharya, learned advocate, who, in fact, represents one of the writ petitioners has volunteered to sponsor five wheel chairs.
23. Mr. Paritosh Sinha, learned advocate and Secretary of the Incorporated Law Society has also agreed to sponsor ten wheel chairs. With this sponsorship, twenty wheel chairs can be purchased and as directed above, the parents of one of the children suffering from Muscular Dystrophy shall obtain a

proforma invoice from the concerned company,
which is supplying foldable wheel chairs at
affordable cost.

24. List the matters on 22nd July, 2025.

(T.S SIVAGNANAM)
CHIEF JUSTICE

(CHAITALI CHATTERJEE (DAS), J.)