

22.07.2025
Item Nos.1 to 3
RP/PG
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
Mr. Suman Chattopadhyay

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

W.P.A. 6300 of 2023 &
W.P.A. (P) 9 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 1st July, 2025 in which we had requested the assistance of the learned Additional Solicitor General. Paragraphs 13 and 14 of the order are quoted hereinbelow:

“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."

2. The Director, National Institute for Locomotor Disabilities (Divyangjan) (hereinafter referred to as NILD'), Kolkata has given written instructions dated 21st July, 2025 to the learned Additional Solicitor General giving their response to the clarifications sought for in paragraphs 13 and 14 of the order dated 1st July, 2025, which has been quoted hereinabove. For a better appreciation, the response received from the Director, NILD is quoted hereinbelow:

"Yes, persons suffering from Muscular Dystrophy may require assistive devices such as Ankle Foot Orthoses (AFO), night splints for the legs, knee orthoses, and spinal braces to support mobility and prevent deformities. These devices are provided free of cost under the Scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances (ADIP Scheme) of the Government of India by the Pradhan Mantri Divyasha Kendra (PMDK), ALIMCO (Artificial Limbs Manufacturing Corporation of India) situated at NILD (National Institute for Locomotor Disabilities (Divyangjan), Kolkata.

3. In terms of the above response, it is clear that the Assistive devices will be provided free of cost in

terms of the Scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances (ADIP Scheme) of the Government of India, which is situated and NILD, Kolkata. Therefore, we direct that all those persons, who are suffering from Muscular Dystrophy to apply for the required assistive devices, duly accompanied by a Doctor's certification certifying that the person requires such devices. Upon such application, if made to the NILD, the same shall be processed and the assistive devices be provided free of cost under the Scheme at the earliest, preferably within a period of four weeks from date on which the application is made.

4. We place on record our appreciation for the efforts taken by the learned Additional Solicitor General of India.
5. In paragraph 16 of the order dated 1st July, 2025, the following request was made to the learned Additional Solicitor General of India:

"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."

6. The learned Additional Solicitor General has produced a copy of a Standard Operating Procedure (SOP) to handle the cases where type or percentage of disability or both of PwD has changed; or where PwD who has already been issued UDID card/disability certificate migrates permanently to other State/Union Territory. The SOP also contains a flow-chart.
7. We direct the learned advocates appearing for the petitioners to instruct their clients to upload the necessary details in the portal by following the SOP (copy of which has been handed over to the learned advocates for the petitioners) and inform this Court as regards the outcome of such exercise. In the event there is any hurdle faced by those persons, the same shall be reported before this Court in the form of a report reduced into writing.
8. In paragraph 5 of the order dated 1st July, 2025, certain clarifications were sought for from the State.
The said paragraph is quoted hereinbelow:

“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."

9. Mr. Tapan Kumar Mukherjee, learned senior advocate appearing for the State has produced a copy of the order dated 14th July, 2025 issued by the Medical Superintendent-cum-Vice Principal, IPGME &R-SSKM Hospital, Kolkata. From the said order, it is seen that in compliance with the order passed by this Court, it has been ordered that other supporting medicines (Calcium, Vitamin D3, Pantoprazole (20mg) and Pantoprazole (40mg) and others, as necessary shall also be dispensed along with tablet 'Deflazacort' for a minimum period of two months from the 'Rare Disease Clinic' to the patients suffering from DMD to alleviate the symptoms and for general improvement of health of the patients. The said order is placed on record and the same shall be complied with in terms of the directions issued by the Medical Superintendent-cum-Vice Principal, IPGME &R-SSKM Hospital, Kolkata. The persons suffering from DMD shall make use of this order and obtain the requisite supply of the

medicines for a period of two months from the Rare Disease Clinic.

10. In paragraph 12 read with paragraphs 22 and 23 of the order dated 1st July, 2025, a request was made to the parents of one of the patients suffering from Muscular Dystrophy to obtain a proforma invoice from the company, which supplies wheel chairs at very affordable rates. Accordingly, one of the parents has produced a quotation from Home Hospital Private Limited, which shows that the price of one wheel chair will be approximately Rs. 8,809.52/-. On the last occasion, we had recorded the benevolent attitude of the learned advocates appearing for the petitioners in coming forward to sponsor wheel chairs. In order to produce the wheel chairs, we direct all contributions be made to the Muscular Dystrophy Patient Welfare Society, the first petitioner in W.P.A. (P) 20 of 2020. On receipt of the amount, the Society shall arrange for purchase of the wheel chairs and supply the same to the persons, who are in need of the assistance of the wheel chairs. The Society shall make the payment directly to the supplier viz. Home Hospital Private

Limited, whose bank details have also been furnished.

11. It will be open to the other members of the Bar to also come forward to make their contributions, if they so desire.
12. On the last occasion, there were other learned advocates, who also volunteered to sponsor the wheel chairs. Let this order be brought to their notice by the learned advocates appearing for the petitioners.
13. In paragraph 1 of the order dated 1st July, 2025, the Court made a suggestion to the State Government to consider providing a stipend of Rs. 5,000/- to per person suffering from rare diseases and the appropriate authority of the State Government was granted liberty to respond to this suggestion put forth by the Court by filing a report in the form of an affidavit. Mr. Mukherjee, learned senior advocate appearing for the State submitted that the matter is under the active consideration of the State Government and the turn of events will be reported to this Court on the next hearing date.

14. With regard to the facility of exclusive ICU unit for the persons suffering from rare diseases, certain directions were issued in paragraphs 6, 7 and 8 of the order dated 1st July, 2025. The response given by the Head of Department of Neonatology, Nodal Officer, COE of Rare Disease IPGME&R, SSKM Hospital, Kolkata dated 22nd July, 2025 is very encouraging and it appears that a detailed project report with site drawings and vetted estimates and financial implications will be submitted shortly. We request the concerned authorities to expedite the matter and the progress be reported before this Court on the next hearing date.
15. Further it has been stated that increase in the number of OPD days at Rare Disease Clinic and upgradation of existing services for management of rare disease cases at COE, IPGMER, Kolkata is under serious consideration. The provision of trained professionals like full-term Medical Genetist and Consultants from various disciplines, Laboratory Technicians, Paramedical Staffs, Dieticians, Social Workers may be needed in this

regard. Requisite steps be taken so that the facility can be upgraded at the earliest.

16. It is further submitted by the Head of Department of Neonatology, Nodal Officer, COE of Rare Disease IPGME&R, SSKM Hospital, Kolkata that so far as installation of the necessary equipments for sleep study test along with bipap machine etc. are concerned, the said facility is available in SSKM Hospital and necessary steps will be taken to install such equipments in Kolkata Police Hospital and until then, the persons suffering from rare diseases will be tested in SSKM Hospital.
17. It will be appreciated if the said equipments can be provided at the Kolkata Police Hospital at the earliest, preferably within a period of two months.
18. The Head of Department of Neonatology, Nodal Officer, COE of Rare Disease IPGME&R, SSKM Hospital, Kolkata, who is present in Court today submitted that manpower is also required to be put in place. The State Government shall ensure that action be taken simultaneously for providing requisite number of trained professionals/manpower so as to support the system. The State

Government can prioritize this issue and adopt measures so that the recruitment can be completed at the earliest, preferably within a period of three months from date.

19. We place on record the appreciation of Mr. Paritosh Sinha, learned advocate and Secretary of the Incorporated Law Society, whom we have requested to represent two Chambers of Commerce situated in Kolkata.
20. Since as of now the sleep study equipment along with bipap machine is not available in the Kolkata Police Hospital, if the Government can inform as to what would be the price of such equipments, Mr. Sinha would submit that he will try to speak to the concerned persons in the Chambers of Commerce and other philanthropic organisations requesting them to sponsor those equipments.
21. One hurdle, which this Court perceives, is that if equipments are sponsored by benevolent persons, the State Government should be pro-active to accept those equipments in its inventory and take care of its maintenance. In this regard a specific written instruction be furnished by the concerned authority

of the State Government or else, sponsorship of such equipments will become a *fait accompli*.

22. Mr. Kaushik Gupta, learned advocate appearing for the petitioners in W.P.A. (P) 9 of 2023 has highlighted the difficulty faced for obtaining UDID Card. It is submitted that different hospitals follow different operating procedure and there are no standard norms. It is submitted that one of the Government hospitals insists upon the residential certificate to be issued by the Councillor of the local Municipality.

23. We failed to understand as to what will be the necessity of a Councillor of a Municipality or a Pradhan of a Panchayat to give a certificate when there are better documents by which the identity of a person, the permanent residential address, the age etc. can be ascertained. Therefore, all hospitals in the State of West Bengal should adopt a uniform procedure with regard to production of the details for obtaining the UDID Cards and definitely a certificate from the Councillor of a Municipality or a Pradhan of the Panchayat should not be insisted upon but other records can always be accepted such

as AADHAR Card, Ration Card, Bank Pass Book, Voter ID Card, Driving Licence of the parents of the patients suffering from rare disease. In this regard, the appropriate authority of the State Government shall pass an order and such order be placed before this Court on the next hearing date.

24. One other issue, which has been highlighted, is with regard to unavailability of the data in the hospital when there is a change of hospital to which the patient is referred. By way of illustration, it is submitted that one patient has been treated in the R.G. Kar Hospital, who is a resident of Dum Dum and recently he has been directed to take treatment in Salt Lake Seva Hospital but the data has not been migrated from the R.G. Kar Hospital to Salt Lake Seva Hospital. The appropriate authority of the State Government/Authorities of the R.G. Kar Hospital Administration shall ensure that the data of all such persons are migrated immediately as and when the patients are referred to some other hospitals for treatment.

25. Learned senior advocate further pointed out that one of the patients is under treatment at N.R.S.

Hospital and accessibility of the patients is almost next to impossible since there are no ramps provided. Providing ramps and facilities for the persons with disability is a statutory requirement and failure to do so by the State would result in serious consequences. The Public Works Department, West Bengal shall take note of this and provide appropriate facilities so that the patients are able to access all the premises of all the hospitals.

26. List these matters on 12th August, 2025 under the same caption.

(T.S SIVAGNANAM)
CHIEF JUSTICE

(CHAITALI CHATTERJEE (DAS), J.)