

12.09.2025
Item Nos.1 to 3
Ct. No.1
Saikat/Raja

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, Adv.
Ms. Saloni Bhattacharyya, Adv.
Ms. Gulsanwara Pervin, Adv.

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

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

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

Mr. Kaushik Gupta, Sr. Adv.
Ms. Srimoyee Mukherjee, Adv.

....For the Petitioner
in
[WPA(P) 9 of 2023]

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

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

Mr. Kishore Dutta, A.G.
 Mr. Tapan Mukherjee, A.G.P./Sr. Adv.
 Mr. Nilotpall Chatterjee, Adv.
 Mr. Somnath Naskar, Adv.
 Mr. Suddhadev Adak, Adv.

.....For the State

Mr. Suman Chattopadhyay, Adv.

...For the Respondent
 in WPA(P) 9 of 2023

1. We have heard the learned Advocate General and learned counsels appearing for the other respective parties.
2. It is heartening to note that the Government, more particularly the Health and Family Welfare Department, Government of West Bengal has been proactive to the orders which were passed by this Court from time to time and the Director of Medical Education, Government of West Bengal has submitted a report dated 12th September, 2025, (which is taken on record) with regard to the action taken by the Department of Health and Family Welfare in connection with various direction issued in the order dated 28th August, 2025.
3. We are happy and pleased to note that the Department of Health and Family Welfare had taken expeditious steps to comply with the directions and the action taken has been given in a tabular format and for better appreciation, the same is quoted hereunder:-

<i>Paragraph No.</i>	<i>Orders of the Hon'ble Court at Calcutta</i>	<i>Action taken by the Dept. of H&FW</i>
<i>Paragraph No.3</i>	<i>With regard to supply of wheel chairs to the persons affected by the rare disease the learned advocate appearing for the petitioners in WPA (P) 20 of 2020 submitted that order has been placed on the supplier M/s. Home Hospital Pvt. Ltd. for ten chairs and payment has already been effected and it will be distributed on 7th September, 2025. In our order dated 13th August, 2025, in paragraph - 12 we have mentioned about installation of sleep study equipment along with bipap machine and in the same order we have suggested for increasing the clinic to at least two days in a week. The Professor Department of Neonatology, Nodal Officer and COE of Rare Disease IPGME&R, SSKM Hospital, has given a report dated 27th August, 2025, 3 wherein it has been stated that the day of Rare Disease Clinic at COE may need to be increased from one to two per week, provided the additional staffs are appointed from the Department of Health and Family Welfare, Government of West Bengal to the COE to run the OPD. The activities of the multidisciplinary rare disease clinic are in addition to the routine clinical duties of the faculties of COE, IPGME&R, Kolkata.</i>	<i>An order vide no.HFW-38099/22/2025/M/2426 dated 09.09.2025 has been issued by the Department of H& FW, wherein it has been notified to increase the OPD days for Rare Disease Clinic from one day to two days in a week with immediate effect. Copy of the order is annexed with the report and marked as Annexure-1.</i>
<i>Paragraph No.4</i>	<i>In the light of the above report, we direct the Principal Secretary, Department of Health and Family Welfare, Government of West Bengal to provide</i>	<i>Three Specialist Medical Officers have been detailed at IPGMER, CoE in this regard, copy of the order is</i>

	<i>additional staffs to the COE for increasing the number of OPD days. These allotments shall be made within 15 days from the date of receipt of server copy of this order.</i>	<i>annexed with the report and marked as Annexure-II.</i>
<i>Paragraph No.5</i>	<i>With regard to the sleep study equipment, it is stated that the approximate cost of the machine is Rs.30 lakhs. The Principal Secretary, Finance Department, Government of West Bengal and the Principal Secretary, Department of Health and Family Welfare, Government of West Bengal are directed to provide appropriate order, sanctioned funds for purchase of the sleep study equipment along with bipap machine to be installed in the hospital and this may be prioritized and requisite sanction be made at the earliest but not later than 15 days from the date of receipt of server copy of this order.</i>	<i>Two sleep study equipment are available with the SSKM & IPGMER and with the Institute of Psychiatry (IoP). In case additional numbers of machines are required for the work, such additional number of machines would be proved by the Department.</i>
<i>Paragraph No.6</i>	<i>This Court on two previous occasions has made a suggestion to the State Government for providing a stipend of Rs.5000/- per person suffering from rare disease considering the total number of persons who have been registered in the portal. The Court suggested that the approximate number of persons can be fixed at 500 and funds may be made available. Mr. Mukherjee, learned senior government counsel appearing for the State submitted that the matter is under active consideration of the Finance Department. It needs to be pointed out that a report in the form</i>	<i>The issue involves policy decision and hence, the matter is being placed to competent authority. Hence, some more time may be allowed in this regard.</i>

	<i>of affidavit was to be filed by the appropriate authority of the State but no such report has been filed as yet. The Principal Secretary, Department of Health and Family Welfare, Government of West Bengal and the Principal Secretary, Department of Finance are directed to take note of the recommendations made by this Court and appropriate sanction order be issued within 15 days from the date of receipt of server copy of this order and the same be reported before this Court on the next date of hearing.</i>	
<i>Paragraph No.7</i>	<i>We are thoroughly disappointed with the State Government. Any information with regard to the directions/observations and difficulties faced in obtaining UDID Cards and other related matters, it appears that the concerned authorities are not taking the matter seriously and they need to be reminded that if orders of the Court are not obeyed the Court is entitled to initiate suo motu contempt proceeding which may result in unpleasant adverse consequences. Therefore, the appropriate authorities of the State are directed to respond to the observations made and directions issued by this Court in order dated 13th August, 2025, with regard to UDID Cards on the next date, failing which the Court may be constrained to take action under the Contempt of Court's Act.</i>	<i>Information relating to UDID and Disability Certificate issues are attached separately and marked as Annexure-III.</i>

Paragraph No.8	<i>Equally, we are also disappointed with the fact that no action has been initiated with regard to the proposal to provide five bedded ICU unit in the Kolkata Police Hospital in the ground floor in paragraph 11 of the order dated 13th August, 2025, it was observed that the Principal Secretary, Department of Health and Family Welfare, Government of West Bengal shall examine this aspect and request was made to the Principal Secretary to give his personal opinion so that five bedded ICU unit is established. No instruction has been given to the learned advocate appearing for the State and all that we can express is our disappointment.</i>	<i>A 50-bedded Critical Care Block (CCB) is on its verge of completion at Kolkata Police Hospital and would start functioning within two months. Five ICU/CCU beds would be earmarked at this CCB for rare disease patients.</i>
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4. Thus, it could be seen that most of the directions have been complied with and with regard to the UDID and Disability Certificate in the report of Director of Medical Education, a report by ADHS – SBHI/Mental Health & State Coordinator –UDID, Department of H&FW, Government of West Bengal dated 9th September, 2025, has been annexed. We direct the learned advocate appearing for the petitioners to go through the said annexures and if any further clarification is required the same can be placed before this Court on the next hearing date.

5. Ms. Nandini Mitra, learned advocate appearing for the petitioner in WPA(P) 20 of 2020 has submitted that wheelchairs have been purchased and on September 7, 2025, the wheelchairs have been handed over to the children and a photograph in this regard has been placed before this Court which is taken on record.
6. The learned advocate for the petition has also prepared a tabulated statement captioned 'Bullet Points' of the orders which contains dates of the various orders passed by this Court and the directions given from time to time to assist. This is also taken on record. The learned advocate for the petitioner shall keep updated the 'Bullet Points' as and when direction is issued.
7. We also record the presence of Prof. Dr. Suchandra Mukherjee, Head of the Department, Neonatology, Nodal Officer and COE of Rare Disease IPGME&R, SSKM Hospital, Kolkata, and the Court conveys deep sense of appreciation to the learned Professor.
8. One other issue which is flagged is with regard to compulsory prenatal screening for deducting DMD, which is also a rare disease. It is submitted that such screening is available for SMA, which is also one of the rare diseases but definite protocols have not been put in place so far as prenatal screening for DMD.

9. The State Government can explore the possibilities of extending this screening which is now being done for SMA to enable early deduction of DMD cases. The appropriate authority of the Government shall examine the aspect and place their view points in the form of a report.
10. List the matter on 15th September, 2025.

[T.S. SIVAGNANAM]
CHIEF JUSTICE

[CHAITALI CHATTERJEE (DAS), J.]