

05.09.2024
Item Nos.21 to 23
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 & 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
Mr. Samin Ahammed
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
Mr. Tirthapati Acharya
Mr. Arijit Majumder

.....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

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

Mr. Samrat Sen, Ld. A.A.A.G.
 Mr. Anirban Ray, Ld. G.P.
 Mr. T. M. Siddique
 Mr. Nilotpall Chatterjee

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

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

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

1. In terms of the orders passed on 9th May, 2024, notices have been sent to all the Chambers of Commerce and office report states that notices have been served on 18th June, 2024/ 20th June, 2024/ 6th June, 2024. However, since the matters were mentioned and upgraded, in all probabilities, the Chambers of Commerce or their learned advocates might not have noticed the matters.
2. Learned advocate for the petitioners is requested to inform the counsels, who are likely to represent the Chambers of Commerce so that the Court can hear their views and suggestions.
3. Learned advocate for the petitioners submitted that the State of West Bengal pays a sum of Rs.1,000/- for each person suffering from the rare disease, who has been issued the disability card and this amount is very meager

and insufficient to meet the expenses for purchase of the medicines such as steroids for the person suffering from this rare disease. It is submitted that the State of Andhra Pradesh is paying Rs.15,000/- per person per month for such purpose.

4. Learned advocate for the petitioners submitted that the State of Orissa has taken a decision and has paid a lumpsum amount of Rs.10,00,000/- for each person suffering from Muscular Dystrophy disease.
5. Learned advocate for the petitioners would point out that the State in its benevolence is ready to disburse a sum of Rs.85,000/- per club for the Durga Puja festival and the State should be more considerate on the persons, who are suffering from this Muscular Dystrophy disease, which is a degenerative disease and requires constant medical care and attention and physiotherapy.
6. The learned Government counsel is directed to obtain specific written instruction from the highest authority of the State in charge of the subject and file a report in the form of an affidavit on the next hearing date.
7. Learned advocate for the petitioners submitted that there is an alternate medicine, which can

be given for the person suffering from Muscular Dystrophy disease, which is a non-steroid and, therefore, does not have any adverse side effect.

8. Let the relevant particulars such as the name of the drug etc. be furnished to the learned Government counsel to enable the learned Government counsel to get instruction from the highest authority of the State of West Bengal in charge of the subject as to whether this can be provided in the Centre of Excellence in Calcutta.
9. The learned Additional Solicitor General made reference to paragraph 5 of the order dated 9th May, 2024. In the said order, we had directed the Joint Director of Health Services, Government of West Bengal to fix a date and time and give appropriate intimation to the Government of India for conducting the online demonstration as to how the UDID cards have to be downloaded. It is saddened to note that though the order was passed on 9th May, 2024, till date, the meeting has not been convened by the Joint Director of Health Services, Government of West Bengal. Though, the learned Government counsel would submit that on account of certain untoward incidents,

which have occurred in another hospitals, the high officials are busy. To be noted that the order and direction was issued on 9th May, 2024 and not later. When the matter is heard on the next date, the Joint Director of Health Services, Government of West Bengal shall report as to on what date, the meeting will be convened, failing which the Court will be constrained to draw adverse inference and pass necessary further directions.

10. List the matters in the next Thursday (12.09.2024) in the same position.

(T.S SIVAGNANAM)
CHIEF JUSTICE

(HIRANMAY BHATTACHARYYA, J.)