

07.08.2023
Item Nos.14-16
gd/ssd

WPA(P)/20/2020
CAN/1/2023
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.

Mr. Samim Ahammed,
Ms. Gulsanwara Pervin
..for the Petitioners in
WPA(P) 20 of 2020.

Mr. Biswaroop Bhattacharya,
Mr. Siddhartha Sankar Mondal,
Ms. Arunima Das Sharma
..for the Petitioners in
WPA 6300 of 2023.

Mr. Kaushik Gupta,
Ms. Srimoyee Mukherjee
..for the Petitioners in
WPA(P) 9 of 2023.

Mr. Asok Kumar Chakraborti, ld. ASG,
Mr. Arijit Majumdar
..for the Union of India in
WPA(P) 20 of 2020 and
WPA 6300 of 2023.

Mr. S.N. Mookherjee, ld. AG,
Md. T.M. Siddiqui
..for the State in
WPA(P) 20 of 2020.

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. Three issues need to be considered today. The first of which is with regard to the establishment of one more Centre of Excellence within the State of West Bengal.

3. The learned Additional Solicitor General has produced a copy of the communication sent by the Government of India, Ministry of Health and Family Welfare, Department of Health and Family Welfare (Rare Diseases Cell) dated 04.05.2023 addressed to the Principal Secretary, Health and Family Department, Government of West Bengal requesting the Government of West Bengal to identify any of the hospitals or institutions situated in the northern part of the State which can be recognised as a Centre of Excellence and for such purpose, the necessary infrastructure, both in terms of manpower and machinery may be established and intimated to the Department of Health and Family Welfare or the Directorate General of Health Services, Ministry of Health and Family Welfare.

4. The learned Advocate General seeks time to get instruction in this regard and as to what is the response of the State of West Bengal to the

communication received from the Central Government dated 04.05.2023.

5. The petitioners in WPA(P) 9 of 2023 has referred to a communication sent by the Ministry of Social Justice and Empowerment, Government of India dated 29th November, 2022 addressed to all NGOs receiving grant of aid. This concerns the enrolment/registration on the UDID Portal.

6. It is submitted by the learned advocate for the petitioners in WPA(P) 9 of 2023 that till date the identity cards have not been issued to the persons with disability and this is very essential as the card issued by the State of West Bengal can be utilized only within the State and in cases where the persons suffering from several disabilities have to travel to other States and in the event they suffer ill health while during travel, to enable them to get the required medical attention UDID card is essential.

7. The learned Advocate General has referred to the report wherein necessary instructions have been given and from the information submitted in the report it appears that as soon as the enrolment/registration is done on the UDID Portal, the card can be generated online.

8. In this regard the learned advocate for the petitioners seeks time to get necessary instruction in the matter.

9. The learned advocate for the petitioners in WPA 6300 of 2023 has highlighted about the non-availability of particular medicines/drugs, namely, Amondys 45 Cxon Skipping, Vyndoxys 53 Cxon Skipping and Exondys 51 Cxon Skipping to be administered to patients suffering from the rare diseases in particularly DMD to lead a quality life.

10. It appears that the said drugs have to be imported and as of now not being manufactured in India.

11. The mother of the petitioner nos.4 and 5, namely, Smt. Bithika Ghosh is present in court and submits that to her knowledge, pursuant to orders passed by the High Court at Delhi, persons suffering from DMD like her two sons have been administered the aforesaid drugs.

12. The learned Advocate General seeks time to get instruction in this regard as to how best the issue can be addressed by the State Government so that the quality of life of the persons suffering from this rare disease can be made better.

13. In this regard the appropriate authority of the Government of India, Ministry of Health and Family Welfare shall also place on record as to what will be the procedure that has to be adopted for importing such drugs and whether the State of West Bengal can by itself take action for import or the import of the drugs

has to be routed from the Central Government through the Centre of Excellence. The concerned authority of the Government of India, Ministry of Health and Family Welfare may also place on record as to what will be the procedure for the State of West Bengal to procure such drugs to be administered to persons affected by DMD.

14. The petitioner in CAN 1 of 2023 in WPA(P) 20 of 2020 has enclosed a list of persons who have been affected by DMD and there is also a report annexed to the application.

15. The State of West Bengal, Department of Health and Family shall examine the list so as to ensure that all the persons, who have been affected by the rare disease, have been administered the required treatment.

16. The court will consider as to what further directions are required to be passed on the next hearing date after receiving the response from the State Government as well as Central Government on the above aspects.

17. List on 21st August, 2023.

(T. S. SIVAGNANAM)
CHIEF JUSTICE

(HIRANMAY BHATTACHARYYA, J.)