

22.08.2023
Item Nos.10-12
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.

Ms. Nandini Mitra,
Mr. Samim Ahammed,
Ms. Saloni Bhattacharya,
Ms. Gulsanwara Pervin,
Mr. Arka Ranjan Bhattacharya,
Ms. Ambiya Khatoun
..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. Asok Kumar Chakraborti, ld. ASG,
Mr. Suman Chattopadhyay
..for the Union of India in
WPA(P) 9 of 2023.

Mr. S.N. Mookherjee, Id. AG,
 Mr. A. Ray,
 Md. T.M. Siddiqui

..for the State in
 WPA(P) 20 of 2020 and
 WPA(P) 9 of 2023.

Mr. Tapan Kumar Mukherjee,
 Mr. Somnath Naskar

..for the State in
 WPA 6300 of 2023.

1. We have elaborately heard the learned advocates for either of the parties and also taken note of the directions issued in our earlier order dated 07.08.2023.

2. For the time being we propose to concentrate on three issues. The first of which is for providing oral steroids to all DMD children.

3. We note from the report submitted by the Nodal Officer, Centre of Excellence of Rare Disease, IPGME & R, SSKM Hospital, Kolkata dated 12.06.2023 that the oral steroid has not been administered to the DMD children as it has been stated that official procedure has been initiated to supply the same. We are informed by the learned advocates for the petitioners as well as the parent of two of the children who are suffering from this rare disease that till date the oral steroid has not been made available.

4. In our view, administrative problems and bureaucratic approach should not in any manner delay the supply of these live saving drugs to all DMD

children. Therefore, there will be a direction to all the authorities concerned to immediately ensure that the oral steroid is administered to all the DMD children without loss of time. The court will monitor the same and in any event the supply of the medicine shall take place within ten days from date.

5. The next aspect is with regard to the import of three of the live saving medicines, namely, Exondys 51, Vyondys 53 and Anondys 45.

6. Admittedly, the aforementioned medicines are not manufactured in India and have to be imported.

7. It is submitted that pursuant to the order passed by the High Court at Delhi, the medicines have been imported and they have been administered to the children who are admitted under the care and attention of AIIMS, Delhi.

8. Further, from the written instruction given by the Under Secretary, Government of India, Ministry of Health and Family Welfare, Department of Health and Family Welfare (Rare Diseases Cell), New Delhi which was placed before this court by the learned Additional Solicitor General, it has been clearly set out that there are no specific guidelines as of now for procurement of medicines/vaccines for treatment of rare diseases under the National Policy for Rare Disease (NPRD), 2021, issued by the said Department. Further, it has been stated that the procurement of such

medicines are done by the Centre of Excellence for the patients of rare diseases getting treatment at their Centre and there are no restrictions on State Government from procuring the medicines/drugs/injections required for the patients suffering from rare diseases or to bear the cost for such procurement. Further, it has been stated that the Centre of Excellence are to procure the medicines/vaccines/drugs that are required for the treatment of the rare disease patients. That Government of India bears the cost of treatment of rare diseases patients upto Rs.50 lakhs. Further, in the said communication it has been stated that the three meetings of the National Rare Diseases' Committee (NRDC) which has been constituted in compliance of the orders passed by the High Court at Delhi, have been convened and as per the mandate of the Committee, positive discussions were held with some pharma entities for negotiations for reduction of prices of the drugs used for treatment of rare disease patients and other options for central procurement were explored.

9. Thus, unless and until a concrete policy is framed for central procurement, the State of West Bengal has to immediately take steps for importing of such medicines/vaccines/drugs/injections etc. which are required for the patients suffering from the rare

diseases and the cost of procurement of the said medicines has to be borne by the State of West Bengal.

10, Therefore, we direct that the concerned authorities of the State of West Bengal to immediately take steps for import of the aforementioned three medicines and such other medicines/vaccines/drugs/injections which are required to be imported for treatment of patients suffering from rare diseases. The cost of such procurement shall be borne entirely by the State of West Bengal.

11. Considering the need and urgency, the appropriate authorities of the State of West Bengal shall take necessary steps for import and procurement of the medicines/vaccines/drugs/injections as expeditiously as possible, but not later than a period of 30 days from date by adopting a procedure which will enable compliance of the direction within the time frame as we are informed that as per the procurement policy of the State of West Bengal there are several other procedures to be followed which undoubtedly will delay the procurement of these live saving medicines. Therefore, the State Government should consider this as an emergency situation and, accordingly, take steps for import of the medicines.

12. The third aspect which has been pointed out is that the Centre of Excellence which was hitherto

functioning at SSKM Hospital has been all of a sudden shifted to another premises called Kolkata Police Hospital.

13. The learned advocates for the petitioners would submit that the Kolkata Police Hospital has not been functioning and the building was lying vacant and all of a sudden the Centre of Excellence has been shifted there and there are absolutely no facilities available in the said hospital and the minimum facility of wheel chairs are also not available. It is not clear as to on what basis the Centre of Excellence stood shifted to the Kolkata Police Hospital. However, this issue would undoubtedly be within the purview of the concerned professionals who are entitled to take such a decision. However, if the decision has been taken to shift the Centre of Excellence without even providing the basic facilities such as wheel chairs, ramps for the patients etc., the said decision has to be branded as arbitrary and without any thought process. Since a clear picture is not available before the court as to what was the purpose behind shifting the Centre of Excellence to another premises, we refrain from expressing anything further on this issue and would await a report from the appropriate authority on this aspect specifically mentioning as to the need and purpose for which the Centre was shifted.

14. One other question which may crop up is that the Centre of Excellence has been identified and so recognised by the Government of India. Funds are being sanctioned by the Government of India. Therefore, if the centre is shifted to another location is there a requirement of accreditation of that new premises as to whether it meets the requirement stipulated for establishment to be assigned the credit of being the Centre of Excellence.

15. It is rather doubtful as to whether any such exercise was done, however, as observed earlier, we refrain from making any comments on this and we await a report by the concerned authority of the respondent State and we make it clear that the report shall be specific, sincere and setting out all facts which are necessary. The report shall also be duly supported by photographs taken off the said facility. Till the report is filed and the court considers the same there will be a direction to the concerned authority at the Centre of Excellence, Kolkata Police Hospital to immediately procure 15 wheel chairs and make them available in the hospital. The Public Works Department of the concerned region is immediately directed to put up temporary ramps till pacca ramps are constructed in the said premises.

16. One more thought process which can also be given a serious thought by the authorities is that till

the Kolkata Police Hospital is fully renovated and provided with all facilities including sufficient number of beds, clean usable toilets accessible to the patients suffering from rare diseases, a decision can be taken to bring back the Centre of Excellence to the SSKM Hospital and continue to function therein till the Kolkata Police Hospital is made ready with all facilities.

17. The learned advocate appearing for the writ petitioners in WPA(P) 9 of 2023 would point out two paragraphs, namely, paragraphs nos.6 and 7 of the order dated 07.08.2023 which reads as follows:

“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.”

18. It is submitted that the persons who are entitled for being issued the UDID card are unable to make the registration in the said portal and the card cannot be generated online and the portal advises the applicant to approach the District Medical Officer.

19. It is submitted by the learned advocate that the State Government has opened another portal other than the Central Government portal and the patients are thoroughly confused as to in which portal they have to apply for enrolment/registration to enable them to obtain UDID card.

20. The concerned respondent of the State of West Bengal is directed to immediately i.e. within a period of three days from date issue an instruction clearly informing the patients and their caretakers or parents as to through which portal patients have to apply and also list the procedure for making such application. This shall be given wide publicity and shall also be informed to all the patients who visit the hospitals for being administered the treatment or for procuring drugs and pamphlets in this regard be handed over to them in vernacular so that the parents and wards of the patients can immediately seek for enrolment/registration in the said portal.

21. The learned advocate appearing for the petitioners in WPA(P) 20 of 2020 submitted that Smt. Bithika Ghosh has two children, namely, Ritul Ghosh, aged about 14 years and Chiranjeev Ghosh, aged about 7 years, both of whom have been affected by DMD and with the help and assistance of the Member of Parliament, Smt. Bithika Ghosh was able to secure admission for her elder son, namely, Ritul Ghosh in

Kendriya Vidyalaya, Ballygunge and studying now in Class-VI, who is aged about 14 years and his younger brother, namely, Chiranjeev Ghosh is aged about 7 years. However, the mother is unable to secure admission for her younger son in the school as it appears that the Member of Parliament and other important persons are not authorised any more to make recommendations for admissions to seats in Kendriya Vidyalaya.

22. Be that as it may, since her elder son is already studying in the said school, the school may have a policy by which the sibling of the students will also be given admission in the same school.

23. We request the learned Additional Solicitor General to inform the concerned authorities to accommodate Chiranjeev Ghosh, who is aged about 7 years in the same school where his elder brother, Ritul Ghosh is studying in Class-VI as the father of the children, Mr. Benoy Ghosh has quit his job and is staying with his elder son in the school throughout the day as directed by the Institution. Since the father of the child is already in the school, the Institution may not face any difficulty as he would also be able to take care of his younger son, namely, Chiranjeev Ghosh.

24. We hope and trust the Institution will respond to the request made by the learned Additional

Solicitor General as requested by us in this order and do the needful in the matter.

25. We have been compelled to issue this direction considering the very peculiar facts and circumstances of the case though such directions/observations may not strictly fall within the prayer sought for in the public interest litigations.

26. The Nodal Officer has filed an undated report which has been placed before this court stating as to what are the steps taken with regard to the issuance of the UDID card, providing medicines etc.

27. The report is taken on record and the court will monitor the progress on the next date after the directions issued above are complied with.

28. The learned Advocate General submitted that the costs of procurement of the medicines by importing the same has to be borne by the Central Government.

29. In the preceding paragraphs we have referred to the recent instruction given to the learned Additional Solicitor General which clearly sets out that there is no specific guidelines as of now for procurement of medicines/vaccines for treatment of rare diseases under the National Policy for Rare Disease (NPRD), 2021 and the procurement of such medicines are done by the Centre of Excellence and there is no restriction on the State Government for procurement

the medicines required for the patients suffering from rare diseases or to bear the cost for such procurement.

30. Thus, if according to the policy guidelines, the State is entitled to reimbursement of the expenditure it will be well open to the State Government to seek for such reimbursement with the Central Government. However, that shall not deter the State Government from implementing the directions issued above for import of these medicines.

31. List on 25th September, 2023.

(T. S. SIVAGNANAM)
CHIEF JUSTICE

(HIRANMAY BHATTACHARYYA, J.)