

10.10.2023
Item Nos.7-9
gd/ssd/
PG/RP

WPA(P)/20/2020
CAN/1/2023, CAN/2/2023

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. Bikash Ranjan Bhattacharyya,
learned senior advocate
Ms. Nandini Mitra

..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

..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,
Mr. Anirban Ray,
Md. T.M. Siddiqui,
Mr. Suddhadev Adak

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

Mr. S.N. Mookherjee, Id. AG,
Mr. Tapan Kumar Mukherjee,
Mr. Somnath Naskar

..for the State in
WPA 6300 of 2023.

1. By order dated 22.08.2023 among other things we take note of the submission made by the learned advocate for the petitioners in WPA(P) 20 of 2020 that Smt. Bithika Ghosh has two sons and both of them have been affected by DMD and with the help and assistance of the Member of Parliament, Smt. Ghosh was able to secure admission for her elder son in Kendriya Vidyalaya, Ballygunge and he is now studying in Class-VI, who is aged about 14 years. His younger brother, namely, Chiranjeev Ghosh is aged about 7 years and their mother was unable to secure admission for her younger son in the said school as there has been a change of policy and the Members of Parliament are not entitled to make any recommendations.

2. Noticing this situation, we requested the learned Additional Solicitor General to inform the concerned authority to accommodate the younger son of Smt. Ghosh in the same school where her elder son is studying. Further, we noted that the husband of Smt. Ghosh i.e. the father of the children has quit his

job and is staying with his elder son in the school throughout the day as per the directions issued by the Institution. We hope and trust that the Institution will respond to the request made by the learned Additional Solicitor General.

3. The learned Additional Solicitor General submits that soon after the order was passed, he had immediately addressed the Principal of the Kendriya Vidyalaya, Ballygunge about the observations/directions issued by this court and has made the necessary request to accommodate the child in their school.

4. It appears that the Principal of the school has informed that he does not have powers to give such admission, more so when the admission season will start from March, 2024.

5. However, it has been stated that if the Commissioner of Kendriya Vidyalaya Sangathan who is stationed at New Delhi is approached, the matter can be sorted out.

6. Considering the peculiar facts and circumstances of the case and also noting that both the children are affected by DMD and the elder child of Smt. Ghosh is already in the school, it will augur well for the Kendriya Vidyalaya to accommodate the younger child under the sibling quota.

7. Therefore, we request the Commissioner of Kendriya Vidyalaya Sangathan, KVS, 18, Institutional Area, Shaheed Jeet Singh Marg, New Delhi-110016 to consider the case of the writ petitioners and grant admission to the second son, namely, Chiranjeev Ghosh of Smt. Ghosh in the appropriate class for the academic session, 2024.

8. The Registrar General of this court is directed to communicate a copy of this order to the Commissioner of Kendriya Vidyalaya Sangathan, KVS, 18, Institutional Area, Shaheed Jeet Singh Marg, New Delhi-110016 for compliance.

9. Mr. Bikash Ranjan Bhattacharyya, learned senior advocate appearing for the petitioners would submit that in the Kendriya Vidyalaya Sangathan there was no specific quota for sibling.

10. This court has made such an expression because it will always be better for a sibling to study in the same school more particularly in the instant case where the children are suffering from the rare disease. Apart from that the father of the children is in the school throughout the day as per the directions issued by the Institution.

11. In paragraph 3 of the order dated 22nd August, 2023, we took note of the report submitted by the Nodal Officer, Centre of Excellence of Rare Disease, IPGME & R, SSKM Hospital, Kolkata with oral steroid,

which has been administered to the DMD children. It is submitted by the learned senior advocate for the petitioners that though oral steroids have been supplied, the required quantity has not been supplied.

12. The learned Advocate General has assured that the supply shall be effected as per the demand, which will be based upon the prescription that may be issued by the concerned doctor.

13. The other concern expressed by the petitioners is that the stock of the life saving medicines should be increased and should not be calculated on a monthly requirement and at least the requirement for three months should be reckoned. This aspect may also be taken note of by the appropriate authorities.

14. In the same order, we dealt with the aspect regarding import of three life saving medicines viz., Exondys 51, Vyondys 53 and Anondys 45. And after taking note of the submissions made on either side, in paragraph 10 of the order, we directed the concerned authorities of the State of West Bengal to immediately take steps for import of the aforesaid 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 was to be borne by the State of West Bengal.

15. The respondent/State has filed I.A. No. CAN 2 of 2023 to vary and/or modify these directions issued in the order dated 22nd August, 2023.

16. After we have elaborately heard the learned advocates for the parties, we are of the view that a response is required to be filed by the appropriate authority of the Central Government. The learned Additional Solicitor General also request that the Central Government may be granted reasonable time to respond to the prayer for modification.

17. It is brought to our notice that a petition under Article 32 of the Constitution has been filed on behalf of 251 persons, majority of whom are minors suffering from Muscular Dystrophy. The Writ Petition (Civil) No. 1012 of 2023 was heard by the Hon'ble Supreme Court and by order dated 6th August, 2023, notice has been ordered to be served on the Central Agency and the learned Additional Solicitor General, New Delhi has been directed to assist the Court on the issues raised.

18. In the light of the above, the direction issued in paragraph 10 of our order dated 22nd August, 2023 is suspended for the present.

19. The appropriate authority of the Central Government and such other authorities are directed to file their affidavits in I.A. No. CAN 2 of 2023.

20. The next aspect, which we dealt with in the order dated 22nd August, 2023 is with regard to the infrastructural facilities, which are to be provided in the Kolkata Police Hospital. A report has been filed by the Professor and Head of the Department of Neonatology, Nodal Officer of the Rare Disease Committee, Kolkata. The recent report is dated 22nd September, 2023 and the same is taken on record. From the report, we find that there is significant progress in the upgradation of facilities at the Kolkata Police Hospital. The toilet exclusively to be provided for the persons suffering from rare disease is in the process of being constructed. The wheel chairs have been procured.

21. The concern expressed by the learned advocate for the petitioners is that the DEXA SCAN facilities is not available. The learned Advocate General on instruction, would submit that DEXA SCAN is required only once a year and that facility is available in the SSKM Hospital and persons, who are required to undertake the scan, are to be transported from Kolkata Police Hospital to SSKM Hospital. In this regard, an automated ambulance or a vehicle convenient for such persons suffering from rare diseases should be made available in the Kolkata Police Hospital for transporting them to the SSKM Hospital as and when a need arises.

22. The State shall endeavour to upgrade the facilities at the Kolkata Police Hospital in all respects in

a phased manner and also ensure that the doctors, who are posted in the hospital in the rare diseases department shall be preferably retained and not shifted to any other hospital.

23. The next aspect was with regard to establishment of Centres of Excellence. The learned Advocate General on instruction, would submit that creating the infrastructure is not the issue but the expert manpower, which is required to man such Centres of Excellence and it is very difficult to recruit persons with such high qualifications. The said submission is taken on record.

24. The Joint Director of Health Services, Department of Health and Family Welfare, Government of West Bengal has filed a report dated 22nd September, 2023 with regard to disability certificates as well as UDID Cards. The said report is taken on record.

25. In cases, where the applicants, who had applied earlier or have not got their certificates or Cards, such persons are directed to apply afresh through ICON portal and follow the steps and obtain the Cards and certificates.

26. List these matters on 5th December, 2023.

27. We make it clear that though certain individuals and organisations have filed these writ petitions, this order will not be restricted to the writ

petitioners and the order will cover all cases, where persons are suffering from rare diseases.

(T. S. SIVAGNANAM)
CHIEF JUSTICE

(HIRANMAY BHATTACHARYYA, J.)