

02.05.2024
Item Nos.29-31
gd/ssd

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.

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 Bhattacharjee,
Mr. Siddhartha Sankar Mandal,
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. Arijit Majumdar
..for the Union of India in
WPA(P) 20 of 2020 and
WPA 6300 of 2023.

Mr. Suman Chattopadhyay
..for the Union of India in

WPA(P) 9 of 2023.

Md. T.M. Siddiqui,
Mr. Suddhadev Adak
..for the State in
WPA(P) 20 of 2020 and
WPA(P) 9 of 2023.

Mr. Somnath Naskar,
Ms. Debdooti Dutta
..for the State in
WPA 6300 of 2023.

1. Pursuant to the directions issued on 07.03.2024 the learned advocate appearing for the Ministry of Health and Family Welfare, Government of India has obtained written instruction from the said Department dated 28.03.2024.

2. From the written instruction it is seen that the Ministry of Health and Family Welfare has taken effective steps to ensure that the Corporates shall contribute funds for the treatment and research of rare diseases under the Corporate Social Responsibility and it appears that there is still much to achieve in this regard. It is important to note that the Ministry of Health and Family Welfare has taken another proactive step by sensitizing the Public Sector Undertakings under the Ministry of Health and Family Welfare to be role models and set a precedence by contributing a percentage of the profit each year exclusively for the treatment of rare diseases patients under the Corporate Social Responsibility (CSR). The Ministry of Corporate Affairs by Office Memorandum

dated 27th August, 2021 has highlighted that item (i) of Schedule VII includes promoting health care including preventive health care and under the said head companies can undertake activities related to treatment of patients suffering from rare diseases subject to compliance of the provisions of CSR Rules and Guidelines issued thereunder from time to time. Attention was also invited to the fact that as per the data filed by companies in MCA 21 Registry upto 31st March, 2021 a total amount of Rs.16,702 crores has been spent by the companies under the Head “Health Care” which is approximately 18% of the total CSR expenditure incurred. Further, attention was invited to Section 181 of the Act which enables a company to contribute to bonafide and charitable funds, subject to conditions mentioned in the said Section.

3. Thus, what is required to be done is to sensitise the Corporates and to convince them to exclusively contribute for the treatment of patients suffering from rare diseases under Corporate Social Responsibility. The scope of this writ petition cannot be expanded Pan India but at least the court can make an attempt to extend it to the Corporates in the State of West Bengal. To enable to reach the Corporates they have to be informed about the need of the patients suffering from rare diseases.

4. It has been suggested that the various Chambers of Commerce which are actively carrying on activities in the State of West Bengal may be put on notice and their views and suggestions can be invited as to whether their Members who are Corporate Houses in the State of West Bengal can consider and donate a portion of the CSR exclusively for treatment of the patients suffering from rare diseases in the State of West Bengal.

5. The learned advocates for the petitioners seeks time to revert back to get the appropriate information/details so as to enable the court to pass further orders.

6. The learned advocate for the petitioners pointed out that in the hospital where the patients suffering from rare diseases are being treated there is no weighing machine which enables to measure the weight of the patient keeping the patient seated.

7. It is submitted that such a facility is required since most of the patients are wheel-chair bound and unable to stand.

8. Mr. T.M. Siddique, learned Government counsel, on instruction, would submit that immediate steps will be taken to procure such weighing machine and compliance will be reported on the next hearing date.

9. It is further submitted that the patients who are suffering from rare diseases are in a state of depression and require counseling for which the services of a Clinical Psychologist is required. Since the clinic is conducted every Wednesday, the learned Government counsel is directed to get instruction as to whether a clinical psychologist from SSKM Hospital could be made available on every Wednesday to counsel the patients and the children who are suffering from rare diseases.

10. Earlier this court had issued directions for admitting a child in the Kendriya Vidyalaya, Ballygunge Campus.

11. In this regard, directions were issued and with the able assistance and persuasion of the learned Additional Solicitor General and the orders of the Commissioner of Kendriya Vidyalaya Sangathan, New Delhi and the Principal of Kendriya Vidyalaya, Ballygunge the child has been admitted in Class-II and the parent of the child who is present in court expresses her sincere thanks and appreciation to the authorities of Kendriya Vidyalaya Sangathan and in particular, to the learned Additional Solicitor General as also to Ms. Rajarshi Venkat Kundaliya who had appeared for the Sangathan on the earlier dates.

12. This court also records its appreciation for the steps taken by the learned Additional Solicitor

General Mr. Asok Chakraborti for the effective steps taken to admit the child in the school. The Commissioner of Kendriya Vidyalaya Sangathan, New Delhi is also appreciated for the orders passed facilitating the admission of the child and also the Principal of Kendriya Vidyalaya, Ballygunge for the support for the cause.

13. With regard to the UDID Cards it is submitted by Mr. Gupta, learned advocate appearing for the petitioners in WPA(P) 9 of 2023 still the patients suffering from rare diseases are unable to get their UDID Card.

14. The learned counsel appearing for the State submitted that the State of West Bengal is not issuing any Cards and it has to be downloaded directly from the Portal of the Central Government.

15. However, since the children who are suffering from rare diseases would not be very conversant as to how to download the Cards, the appropriate authority of the State Government shall draft a notice in English as well as in Regional Language mentioning about the steps to be followed for the purpose of obtaining such Card.

16. A sample of such notice be placed before this court on the next hearing date.

17. The concerned department officials shall also demonstrate how it is being done to Mr. Gupta,

learned advocate appearing for the petitioners in
WPA(P) 9 of 2023.

18. List these matters on 9th May, 2024.

(T. S. SIVAGNANAM)
CHIEF JUSTICE

(HIRANMAY BHATTACHARYYA, J.)