

12.09.2024
Item Nos.20-22
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 Khatoon

..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.

Ms. Srimoyee Mukherjee

..for the Petitioners in
WPA(P) 9 of 2023.

Mr. Asok Kumar Chakraborti,
Id. Additional Solicitor General,
Mr. Tirtha Pati Acharya,
Mr. Arijit Majumdar

..for the Union of India.

Md. T.M. Siddiqui

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

Mr. Somnath Naskar
..for the State in
WPA 6300 of 2023.

1. In terms of the directions issued in paragraph 9 of the order dated 05.09.2024 it appears that a camp was conducted for the online demonstration as to how UDID cards have to be downloaded.

2. The petitioners would submit that no proper intimation was given though the written request to the said effect was made to the authority.

3. We do not wish to go into the controversy but we would direct the Joint Director of Health Services, Government of West Bengal to conduct one more camp after due intimation in writing. The Joint Director of Health Services can also prepare a flow-chart in regional language as well as in English as to the steps to be followed for downloading and hard copy of the same can be handed over to the persons who attend the camp and we also place on record a notice given by Mr. Sinha from the Under Secretary, Ministry of Health, Government of India who appeared online and apprise the court about the proceedings which are now being dealt with by the Hon'ble High Court at Delhi.

4. With regard to the amount paid by the State of West Bengal to each of the persons suffering from rare

disease which is presently Rs.1,000/- which is observed in paragraphs 3 and 4 of the order dated 05.09.2024 that it is a sum of Rs.1,000/- is grossly insufficient to meet the expenses for purchase of medicines.

5. The learned Government counsel submitted that Rs.1,000/- is being disbursed pursuant to an order passed by the Government in the year 2020 and presently he is awaiting appropriate instruction from the authorities.

6. However, we wish to point out that it is high time for the Government of West Bengal to revise the said amount as the persons suffering from rare disease require such assistance.

7. The learned advocate appearing for the writ petitioners is permitted to contact the Chamber of Commerce and request them to enter appearance before this court on the next hearing date.

8. With regard to the drug to be given to the persons suffering from rare disease, the learned Government counsel has got the following written instruction:

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Date: 12.09.2024

COST CALCULATION

Givinostat is the first oral nonsteroidal drug approved to treat DMD in children aged 6 years and older.

The drug has been recently approved by the US FDA in March, 2024.

The drug is not available in India, and can be imported in the name of the patient through some registered Pharma network.

The drug is not yet approved by DCGI, neither it is recommended by GOI, to be procured under NPRD.

The clinical trial has been done in the US and available evidence of efficacy is still very scanty for routine recommendations.

The cost for a 10 -20 kg child is around 4 Cr per year.

Sd/-
12/9/24

Prof. (Dr.) Suchandra Mukherjee
HOD, Dept. of Neonatology
Nodal Officer
COE of Rare Disease
IPGME & R SSKM Hospital
Kolkata-20"

9. The learned advocate for the petitioners submitted that the above instruction may not be fully correct since the doctors in West Bengal are prescribed the said drug and she has got copies of prescription.

10. In any event it is stated that the Drug Controller of India is yet to approve the said drug.

11. The learned Additional Solicitor General is requested to get instruction from the concerned authority as to whether the approval of the drug is being processed or as to any other decision taken by the Drug Controller of India.

12. The report regarding the camp conducted for downloading UDID Cards handed over by the learned Government counsel is taken on record.

13. List these matters on 19th September, 2024.

(T. S. SIVAGNANAM)
CHIEF JUSTICE

(HIRANMAY BHATTACHARYYA, J.)