

25.04.2023
Ct. No.1
Item Nos.3, 4 & 5
PG/KS

W.P.A.(P) 20 of 2020

Muscular Dystrophy Patient Welfare Society & Anr.
-Vs.-
Ministry of Health & Family Welfare & Ors.

With

W.P.A. 6300 of 2023

Yuvaan Singh & Ors.

-Vs.-

Union of India & Ors.

With

W.P.A.(P) 9 of 2023

Parivaar Bengal & Anr.

-Vs.-

State of West Bengal & Ors.

Mr. Bikash Ranjan Bhattacharya, Sr. Adv.
Ms. Nandini Mitra
Mr. Samin Ahammed
Ms. Saloni Bhattacharyya

.....For the Petitioners
in
(W.P.A.(P) 20 of 2020)

Mr. Biswaroop Bhattacharya
Mr. Sidhdhatha Sankar Mandal
Ms. Arunima Das Sharma

.....For the Petitioners
in
(W.P.A. 6300 of 2023)

Mr. Kaushik Gupta
Ms. Srimoyee Mukherjee

.....For the Petitioners
in
(W.P.A.(P) 9 of 2023)

Mr. Asok Kumar Chakraborti
Mr. Arijit Majumder

.....For the U.O.I.
in

W.P.A.(P) 20 of 2020) &
W.P.A. 6300 of 2023

Mr. S. N. Mookherje, Ld. A.G.
Mr. T. M. Siddique
Mr. Nilotpal Chatterjee

.....For the State
in
(W.P.A.(P) 20 of 2020)

Mr. S. N. Mookherje, Ld. A.G.
Mr. Samrat Sen, Ld. A.A.A.G.
Mr. Anirban Ray, Ld. G.P.
Mr. T. M. Siddique
Mr. Nilotpal Chatterjee

.....For the State
in
& (W.P.A.(P) 9 of 2023)

Mr. Tapan Kumar Mukherjee, Sr. Adv.
Ms. Debdooti Dutta

.....For the State
in
(W.P.A. 6300 of 2023)

1. Pursuant to the order passed on 17th April, 2023, there have been some developments and the learned Advocate General has placed before us a report dated 24th April, 2023 submitted by the Director, I.P.G.M.E.& R, Kolkata. The said report is taken on record and from which, we find that number of enlisted cases are 34, the total number of application received is 25 and the total number of registered cases is 22 (16DMD/6 Non DMD) and number of uploaded cases is 16 (All DMD cases).

2. With regard to the uploading of the information of these patients suffering from rare diseases, it has been stated on the last occasion that an integration has to be done with the portal, which may take a month's time. It is an admitted fact that State of West Bengal was very late to establish the portal, which has contributed to the delay.
3. We are of the view that there should be no further delay and the concerned authority should take steps on a war footing so that the relevant details are uploaded in the portal at the earliest. As rightly pointed out by the learned advocate appearing for the writ petitioners in W.P.A.(P) 9 of 2023, the purpose behind uploading in the portal and issuance of UDID card is not only for treatment but there are other benefits, which have been extended such as full course fee waiver for those students of various courses at all NIs/CRCs, who are UDID card holders. Furthermore, a person suffering from such rare disease, if he happens to travel outside the State of West Bengal unless and until the UDID card is available, he will not be in a position to get treatment in the other States or for such benefits, if the concerned person is pursuing a

course of study or matters related therein. Therefore, the issuance of the UDID card is of utmost importance and the concerned authorities of the State of West Bengal should give a serious thought to the matter and avoid unnecessary delay in making the web portal functional and uploading all the data.

4. With regard to financial support, it is submitted by the learned Advocate General that regardless of the fact as to whether UDID cards have been issued to persons suffering from rare diseases, if those persons are brought to the centre of excellence at Kolkata, they will be examined and necessary follow up action with regard to treatment will be taken care of in the centre of excellence apart from the State reimbursing their entire travel expenses from whichever place they had travelled to consult with the doctors at the centre of excellence. This submission made on behalf of the State of West Bengal is placed on record and the appropriate authority of the concerned department shall ensure that whenever such persons suffering from such rare diseases come to the centre of excellence, they should not only be examined, screened and treatment be effected but the cost incurred by them to undertake the journey to

reach the centre of excellence should be promptly reimbursed. In this regard, an order can always be passed by the concerned authority of the State Government, which will clear any ambiguity in the minds of those persons, who are suffering from such rare diseases.

5. The writ petitioners viz., the society and the individual writ petitioners shall also use their resources to identify such of those persons, who are suffering from such rare diseases and assist them in travelling from other parts within the State of West Bengal to the centre of excellence for being treated for such rare diseases.
6. With regard to 11 persons on whose behalf W.P.A. 6300 of 2023 had been filed, which has been tagged alongwith these public interest litigations, the learned advocate for the petitioners submitted that with the efforts taken by the learned Advocate General, the names of the 11 persons have been uploaded but other follow up action is required to be taken and we are confident that the concerned department of the State of West Bengal shall ensure that all follow up action should be taken

consequent upon the uploading of the names of those 11 persons.

7. On the last occasion this Court posed a query as to whether one more centre of excellence can be established within the State of West Bengal as people from the northern part of the State would find it difficult to travel to Kolkata. We find that there are guidelines for such purpose and unless and until the necessary infrastructure is available, a centre cannot be notified as a centre of excellence. Therefore, we would have advised the State Government to identify any of the hospitals or institutions situated in the northern part of the State, which can be recognized as a centre of excellence and for such purpose the necessary infrastructure, both in terms of manpower and machinery can be established and intimated to the Central Government, who, on inspection can take appropriate action for notifying that hospital or institution as a centre of excellence. Effective steps be taken in this regard within a period of six months from date.
8. The learned Additional Solicitor General has placed before this Court an affidavit filed on

behalf of the first respondent viz., the Department of Health and Family Welfare, Government of India. In the said affidavit, it has been stated that the financial support entitled for the patients suffering from any category of rare diseases will be up to Rs.50,00,000/- as per the office memorandum dated 19th May, 2022. The financial support will be provided to the patients for their treatment in any of the centre of excellence mentioned in the policy. It is further stated that in accordance with the guidelines dated 11th August, 2022 and the 2021 policy, a sum of Rs. 1,20,00,000/- was released on 7th December, 2022 against four patients and on a further request from the centre of excellence at Kolkata, a sum of Rs. 46,40,000/- has been released on 20th March, 2023 for four patients suffering from rare diseases. The documents in support of such averment has been annexed to the affidavit. The affidavit filed by the Central Government is taken on record.

9. Since we are inclined to monitor the matter, further progress in the matter shall be reported by the concerned authority of the State

Government by way of a further report on the next hearing date.

10. As observed earlier, the issue relating to the web portal is of utmost seriousness. It is rather surprising to note that in the State of West Bengal the number of UDID cards generated as on 16th October, 2022 is only 9. The figures, which have been given in respect of other States are phenomenal and we find that West Bengal is the only State, which has got a single digit figure. This position does not augur well for the system as well as the State.

11. Therefore, the Principal Secretary, Department of Health and the Principal Secretary, Department of Women & Child Development and Social Welfare, Government of West Bengal should take up this matter with utmost seriousness and as this Court is monitoring the matter, any unnecessary delay will not be appreciated and the authorities should not come to adverse notice. This direction should be taken in the right spirit and not as an adversarial direction as the State is under a Constitutional obligation to protect the health of its citizens.

12. Let further report be filed two days before the next hearing date after serving advance copies on the learned advocates appearing for the parties and the learned Additional Solicitor General.
13. The learned advocate appearing for the writ petitioners in W.P.A.(P) 20 of 2020 submitted that she has got a list of persons, who have already been identified of suffering from the rare diseases and those persons should be administered treatment immediately.
14. Let the list be furnished to the learned Advocate General, who shall, in turn, direct the concerned authority to look into the matter so that the grievance expressed is redressed.
15. List these matters on 13th June, 2023 in the same position.

(T. S. SIVAGNANAM)
ACTING CHIEF JUSTICE

(HIRANMAY BHATTACHARYYA, J.)