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* **IN THE HIGH COURT OF DELHI AT NEW DELHI**

+ W.P.(C) 5315/2020 & CM. No. 19189/2020

32 MASTER ARNESH SHAW Petitioner
 versus
UNION OF INDIA & ANR. Respondents

AND

+ W.P.(C) 10782/2020 & CM. No. 33828/2020

33 AVIRAJ GARG, AGE 4 YEARS, THROUGH: HIS NEXT FRIEND
AND NATURAL FATHER SH. ABHINAV
GARG Petitioner
 versus
UNION OF INDIA & ANR. Respondents

AND

+ W.P.(C) 322/2021 & CM. No 812/2021

34 KESHAV SHARMA AGE 12 YEARS THROUGH: HIS NEXT
FRIEND AND NATURAL FATHER SANJEEV
KUMAR Petitioner
 versus
UNION OF INDIA & ANR. Respondents
 Through:

AND

+ W.P.(C) 1491/2021 & CM. No. 4291/2021

35 MASTER MEDHANSH JHAWAR @
MADHAV Petitioner
 versus
UNION OF INDIA & ANR. Respondents

AND

+ W.P.(C) 1511/2021 & CM. Nos. 4331/2021 and 4332/2021

36 MASTER KENIT JHAWAR @ KESHAV Petitioner
 versus

UNION OF INDIA & ANR. Respondents
AND
+ W.P.(C) 1611/2021 & CM. No. 4600/2021
37 LAKSHYA KUMAR GOYAL, 8 YRS OLD, THROUGH: HIS
NEXT FRIEND AND NATURAL FATHER SH.
VIPIN KUMAR Petitioner
 versus
UNION OF INDIA & ANR. Respondents
AND
+ W.P.(C) 3682/2021 & CM. No. 11153/2021
39 HARSHIT SONI, 16 YEARS OLD, THROUGH: HIS NEXT
FRIEND AND NATURAL FATHER SH. TIKAM
CHAND SONI Petitioner
 versus
UNION OF INDIA & ANR. Respondents
AND
+ W.P.(C) 3689/2021 & CM. No. 11179/2021
40 DHANANJAY BHARDWAJ, 11 YEARS OLD, THROUGH: HIS
NEXT FRIEND AND NATURAL FATHER SH. AMIT
KUMAR Petitioner
 versus
UNION OF INDIA & ANR. Respondents
AND
+ W.P.(C) 3706/2021 & CM. No. 11229/2021
41 KHUSHWANT BHARDWAJ, 7 YEARS OLD, THROUGH: HIS
NEXT FRIEND AND NATURAL FATHER
SH. NIKHIL BHARDWAJ Petitioner
 versus
UNION OF INDIA & ANR. Respondents
AND
+ W.P.(C) 3707/2021 & CM. No. 11230/2021
42 AARAV GARG, 5 YEARS OLD, THROUGH: HIS NEXT FRIEND
AND NATURAL FATHER SH. VIVEK Petitioner
 versus
UNION OF INDIA & ANR. Respondents

AND

+ W.P.(C) 3729/2021 & CM. No. 11269/2021

43 MANISH, 8 YEARS OLD, THROUGH: HIS NEXT FRIEND AND
NATURAL FATHER SH. PHOOL CHAND JAT
& ANR. Petitioners

versus

UNION OF INDIA & ANR. Respondents

AND

+ W.P.(C) 3737/2021 & CM. No. 11277/2021

44 SHOURYA MARU, 7 YEARS OLD, THROUGH: HIS NEXT
FRIEND AND NATURAL FATHER SH. KAMAL
KUMAR MARU Petitioner

versus

UNION OF INDIA & ANR. Respondents

AND

+ W.P.(C) 3859/2021 & CM. No. 11647/2021

45 SIDDHARTH SWARNKAR, 9 YEARS OLD, THROUGH: HIS
NEXT FRIEND AND NATURAL FATHER SH. DINESH KUMAR
SWARNKAR Petitioner

versus

UNION OF INDIA & ANR. Respondents

AND

+ W.P.(C) 4045/2021 & CM. No. 12213/2021

46 UTKARSH INDRAJIT PAWAR, 10 YEARS OLD, THROUGH: HIS
NEXT FRIEND AND NATURAL FATHER SH. INDRAJIT
DAMAR PAWAR Petitioner

versus

UNION OF INDIA & ANR. Respondents

AND

+ W.P.(C) 4067/2021 & CM. No. 12306/2021

47 ANSHU, 10 YEARS OLD, THROUGH: HIS NEXT FRIEND AND
NATURAL FATHER SH. NARENDRA KUMAR
YADAV Petitioner

versus
UNION OF INDIA & ANR. Respondents
AND
+ W.P.(C) 4259/2021 & CM. No. 12948/2021
48 ISHAAN, 10 YEARS OLD, THROUGH: HIS NEXT FRIEND AND
NATURAL FATHER SH. RAJVIR SINGH Petitioner
versus
UNION OF INDIA & ANR. Respondents
AND
+ W.P.(C) 4304/2021 & CM. No. 13108/2021
49 TANAV HANDOO, 6 YEARS OLD, THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SH. AMIT
HANDOO Petitioner
versus
UNION OF INDIA & ANR. Respondents
AND
+ W.P.(C) 4551/2021 & CM. No. 13949/2021
50 SHAURYA DAHIYA, 7 YEARS OLD, THROUGH: HIS NEXT
FRIEND AND NATURAL FATHER SH.
SATBIR DAHIYA Petitioner
versus
UNION OF INDIA & ANR. Respondents
AND
+ W.P.(C) 4812/2021 & CM. No. 14844/2021
51 NIKHIL YOGENDERSINGH CHOUDARY, 17 YEARS OLD,
THROUGH: HIS NEXT FRIEND AND NATURAL FATHER SH.
YOGENDERSINGH P CHOUDARY Petitioner
versus
UNION OF INDIA & ANR. Respondents
AND
+ W.P.(C) 5394/2021 & CM. No. 16683/2021
52 UDAYVEER SINGH GULERIA, 7 YEARS OLD, THROUGH: HIS
NEXT FRIEND AND NATURAL FATHER SH. RAMESH
GULERIA Petitioner
versus
UNION OF INDIA & ANR. Respondents

AND

+ W.P.(C) 5395/2021 & CM. No. 16686/2021

53 MASTER AYUSHMAN CHATURVEDI Petitioner

versus

UNION OF INDIA & ORS. Respondents

AND

+ W.P.(C) 9684/2021

54 AADHYAN JAISWAL 11 YEARS OLD THROUGH: HIS NEXT
FRIEND AND NATURAL FATHER SH ANIL KUMAR
JAISWAL Petitioner

versus

UNION OF INDIA & ORS. Respondents

Presence: Mr. Sidharth Luthra, Sr. Adv. with Mr. Rahul Malhotra
and Mr. Asif Ahmed, Adv. for petitioner in W.P.(C)
5315/2020

Mr. Chetan Sharma, ASG with Mr. Ripudaman
Bharadwaj, CGSC and Mr. Rishikant Singh, Adv. for
UOI in W.P.(C) 5315/2020

Mr. Ashok Agarwal and Mr. Kumar Utkarsh, Adv. for
petitioners in WP(C) 10782/2020, WP(C) 322/2021,
WP(C) 1611/2021, WP(C) 3682/2021, WP(C)
3689/2021, W.P.(C) 3706/2021, W.P.(C) 3707/2021,
W.P.(C) 3729/2021, W.P.(C) 3737/2021, W.P.(C)
3859/2021, W.P.(C) 4045/2021, W.P.(C) 4067/2021,
W.P.(C) 4259/2021, W.P.(C) 4304/2021, W.P.(C)
4551/2021, W.P.(C) 4812/2021, W.P.(C) 5394/2021,
W.P.(C) 9684/2021

Mr. Rahul Malhotra, Adv. for petitioner in W.P.(C)
1491/2021 and W.P.(C) 1511/2021

Mr. Ranvir Singh, CGSC for UOI in W.P.(C) 3737/2021
and WP(C) No. 4812/2021

Mr. Prakash Kumar, Central Govt. Sr. Counsel for
Respondent No.-1/UOI in W.P.(C) 1511/2021

Mr. Tanveer Oberoi, Adv. for AIIMS

Mr. Sanjib Kumar Mohanty, Senior Panel Central Govt.
Counsel with Mr. Amit Acharya, Advocate for UOI in

W.P.(C) 3706/2021

Mr Satya Ranjan Swain, Central Government Senior Panel Counsel with Mr. Kautilya Birat, Adv. for R-1 in WP (C) No. 4304/2021

Mr. Chetan Sharma, ASG with Mr. Ajay Dignpaul, CGSC and Mr. Kamal R Dignpaul, Adv. for Respondent/IOI in WP(C) No. 322/2021

Mr. Dhanesh Relan, Standing Counsel for SDMC, with Mr. Arindam Dey and Mr. Saubhagya Sundriyal, Advs. for SDMC in W.P.(C) 3706/2021

Mr. Avnish Singh and Ms.Pushplata Singh, Advs. for R-1 in W.P. NO.4551/2021

Mr. Narendra Kumar Srivastava, Senior Panel Counsel for R-1 in W. P(C) 3859/21

Mr. Shankar Kumar Jha, Sr. Panel Counsel, IOI for R-1 in WPC 1611 of 2021 & WPC 3682 of 2021

Mr. Narendra Kumar Srivastava, Senior Panel Counsel for the R-1, W. P. C. 3859/21

Mr. Farman Ali Magray SPC with Mr. Athar Raza Farooquei and Krishan Kumar, Advs. for W.P.(C) 5395/2021 and W.P.(C) 9684/2021

Ms. Saumya Tandon, Adv. for R-2 in W.P.(C) 9684/2021

Mr. Siddharth Khatana, Adv. (Senior Panel Counsel) for Respondent no.1/IOI in W.P. (C) 3707/21

Mr. Sanjeev Sabharwal, Sr. Panel Counsel for IOI in W.P.(C) 4067/2021

Mr. Sanjeev Uniyal, Mr. Dhawal Uniyal and Mr. Sachin Chandela, Advs. for R-1/IOI in WPC NO. 3689/2021

Mr. Niraj Kumar, Sr. Central Government Counsel for R-1 in W.P.(C) No.-5395/2021

Mr. Anurag Ojha, Mr. D.N. Chaturvedi and Mr. Gautam Barnwal, Advs. for petitioners in WPC 5395/2021

Mr. Awadhesh Kumar Singh, Adv. for R-1 in W.P.(C) 5394/2021

Mr. Anuj Aggarwal, ASC, GNCTD with Ms. Ayushi Bansal, Ms. Aishwarya Sharma, & Ms. Sanyam Suri, Advs. for R-2 in WP(C) 3662/2021

CORAM:
HON'BLE MR. JUSTICE V. KAMESWAR RAO

ORDER

01.02.2022

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These matters are being heard through video-conferencing.

1. On the last date of hearing i.e., December 14, 2021, this Court passed a very detailed order wherein this Court has on the issue of the petitioners required to receive necessary treatment as covered under the National Policy for Rare Disease, 2021; with regard to necessary funds being available for the treatment has in paragraph 5, 6, 7 and 8 stated as under: -

“5. In the light of the aforesaid stand taken by the respondent no.1 which shows that they have every intention to ensure that the children covered under the ‘National Policy for Rare Diseases, 2021’ get all the medical assistance they require, I am of the view that once it is an admitted position that petitioners are covered under the said policy promulgated by the respondent no.1 itself for the welfare of persons like the petitioners, they cannot be made to suffer. Any delay in commencement of their treatment may prove to be fatal and defeat the very purpose for which the abovementioned policy was created. I am therefore of the considered opinion that interim directions for commencement of treatment of at least the petitioners before this Court deserve to be issued. It is accordingly directed that the treatment be started forthwith by AIIMS or any of the other Centres of Excellence, as the case may be, details of which Centres have been furnished by the Union of India in its affidavit dated 28.09.2021. The names of these Centre of Excellence are also duly noted in the policy itself. The direction to AIIMS and the other Centres of Excellence to commence treatment of these children would also include a direction to them to provide the necessary medicines to these children, the cost whereof will be borne by the Union of India. It will be the responsibility of the Union of India to ensure that necessary funds are provided to all the

Centres of Excellence, including AIIMS as and when demanded.

6. *It is expected that by the next date, the Union of India will iron out the remaining issues in the working of the policy, so that all other persons covered by the policy are also provided the necessary treatment at the earliest. Needless to state, as assured by the learned ASG, the Union of India shall pursue its application before the Kerala High Court for transfer of the amount of about Rs. 53 crores lying before the said Court, which amount was collected, as already noted in the orders previously passed by this Court for treatment of a child suffering from a rare disease who unfortunately succumbed to the said disease before the said amount could be utilized. This Court also hopes that in the light of the facts emerging from the compilation of extracts of the Annual Returns of PSUs handed over by learned senior counsel for the petitioner in Court, will endeavour to impress upon the PSUs, the importance of diverting at least a part of their CSR contributions towards the fund set up on the online crowd funding website i.e. <http://rarediseases.nhp.gov.in/> created for treatment of the children suffering from rare diseases.*
7. *Needless to state that this amount spent by the Union of India for treatment of these children including the amount for procurement of medicines for the petitioners herein would be adjustable from the funds which are received in the account set up on the specially dedicated portal, or any other appropriate fund created for the said purpose as may be available with the Union of India.*
8. *As except for AIIMS, the other centres of Excellence are not parties before this Court, the learned ASG will ensure that appropriate instructions are issued to all the other Centres of Excellence named in the policy.”*

2. Today all counsels for the petitioners would in unison state that despite efforts to reach out to the authorities for starting the treatment, no response has been received more particularly from by All India Institute of Medical Sciences (‘AIIMS’, hereinafter).

3. Mr. Tanveer Oberoi who appears for AIIMS by conceding that the disease of petitioners in this batch of petitions primarily being DMD / non-DMD, an expert committee has been constituted to undertake the study as to the nature of treatment to be given; to consider the efficacy of the medicines which need to be procured from the manufacturers through indent and the committee report need to be placed before the Government of India for its approval before the treatment can be started.

4. He also states the petitioners having non-DMD disease, after evaluation (in some cases), their details have been uploaded on the portal and with regard to rest shall be uploaded at the earliest. The treatment with regard to those petitioners, can be started after the necessary funds are allocated.

5. Mr. Siddharth Luthra, learned Senior Counsel for the petitioners in W.P.(C) 5315/2020 would contest the stand of Mr. Oberoi on behalf of AIIMS. He states that the submissions have been advanced by Mr. Oberoi were made even on the last date of hearing but the same were negated resulting in the passing of the order on December 14, 2021. In terms thereof the treatment of the petitioners i.e., the children had to start immediately. In fact, obligation was put on the Union of India to ensure appropriate instructions are sent to the Centres for Excellence in that regard as AIIMS is a party in these proceedings.

6. He also states that the petitioner in W.P.(C) 5315/2020 who is based in West Bengal can approach the Centre for Excellence i.e., IPGMER (Institute of Post Graduate Medical Education and Research. Kolkata). He has also drawn my attention to various documents in the affidavits filed by AIIMS to contend that the DMD is a disease recognised under the policy.

He also states that AIIMS has been undertaking the treatment for DMD in the past and in that regard he draws my attention to pages 308-320 of the paper book.

7. According to him, what is being contended by Mr. Oberoi may not be correct as the nature of treatment is known and is being given in the AIIMS. He has also drawn my attention to the affidavit filed by AIIMS on October 26, 2021, more specifically page 11 wherein reference is made to the petitions that are pending before this Court along with the name of the petitioners to state except in respect of three petitioners, with regard to rest, it was clearly stated that they were amenable to treatment for DMD.

8. If that be so, Mr. Luthra states that it is surprising that an institution like AIIMS is still considering through a committee the nature of treatment to be provided to the DMD patients. The treatment has not started even after a lapse of more than one month of the order passed by this Court on December 14, 2021. According to him, the primary reason for the AIIMS not to start the treatment is the sanctioning of the funds.

9. On the last submission of Mr. Luthra, Mr. Oberoi would submit that AIIMS is not in a position to utilise the annual budget sanctioned to the AIIMS, for the treatment of petitioners herein. He also states that insofar as the petitioners who are suffering from Non-DMD disease, they can be directed to report to the Chairman of Rare Diseases, Dr. Madhulika Kabra day after tomorrow, on which date they shall be attended to and the treatment shall be started. I must state here that the submissions made by Mr. Oberoi are not at all appealing. The order passed on December 14, 2021 is very clear that the treatment of the petitioners i.e., children must start immediately. It is surprising that even after a period of one month no

treatment has yet started. Insofar as funds are concerned, the Court in the said order has clearly stated that it is the responsibility of the Union of India to ensure necessary funds are provided to all Centres of Excellence including AIIMS as and when demanded for treatment of these children.

10. Mr. Ripudaman Bhardwaj, learned counsel appearing for the respondent No.1 would submit that the necessary directions in terms of the last order shall be issued to the Centres of Excellence.

11. Noting the submission made by counsels for the parties, it is directed that the respondent No.1 shall issue communication to the AIIMS as well as to the Centres for Excellence for starting the treatment of the petitioners (whichever petitioner approach such a centre, being nearer to the place of residence) without any delay. The instructions must also go to the AIIMS as well by tomorrow fixing the date and time for reporting as 2 PM on February 3, 2022.

12. List the writ petitions for further consideration on March 14, 2022.

13. A copy of this order be kept in all the petitions.

V. KAMESWAR RAO, J

FEBRUARY 1, 2022/ds