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

84

+ W.P.(C) 11610/2017, CM APPL. 27637/2018(Direction)

FSMA INDIA CHARITABLE TRUST Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.

versus

UNION OF INDIA AND ANR. Respondent

Through: Mr. Vijay Joshi and Mr. Vicky
Kumar, Advs. for UOI
Ms. Shyel Trehan, Amicus Curie
with Mr. Raghav Anand, Adv.
Sameer Vashisht, ASC GNCTD with
Ms. Sanjana Nangia, Adv. for R-2.

115

+ W.P.(C) 1182/2022, CM APPL. 3442/2022(Direction)

INSHA MINOR THROUGH HER NEXT FRIEND AND
NATURAL FATHER SH IRSHAD AHMAD SOFI Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.

versus

UNION OF INDIA & ORS. Respondents

Through: Mr. Tanveer Oberoi, Adv. for AIIMS.
Mr. Sanjeev Uniyal, Mr. Dhawal
Uniyal, Mr. Sachin Chandela, Advs.
for UOI.
Mr. T.P. Singh, Advocate for UOI
Mr. Rishikesh Kumar, ASC, GNCTD
with Ms. Sheenu Priya and Mr.
Sudhir Shukla, Advs. for R-4.

116

+ W.P.(C) 322/2021, CM APPL. 812/2021(Direction)

KESHAV SHARMA AGE 12 YEARS THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SANJEEV KUMAR

..... Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar

Utkarsh and Mr. Manoj Kumar, Advs.

versus

UNION OF INDIA & ANR. Respondent

Through: Mr. Ajay Digpaul, CGSC and Mr. Kamal Digpaul, Adv. for UOI.
Mr. Tanveer Oberoi, Adv. for AIIMS

117

+ W.P.(C) 1491/2021, CM APPL. 4291/2021(Direction)
CM APPL. 8671/2022(Direction)
MASTER MEDHANSH JHAWAR @ MADHAV..... Petitioner

Through: Mr. Rahul Malhotra, Mr. Manas Tripathi and Mr. Anshul Gupta, Advocates

versus

UNION OF INDIA & ANR. Respondent

Through: Mr. Satyakam, ASC with Ms. Jyoti Mehra, Adv. for R-1.
Mr. Tanveer Oberoi, Adv. for AIIMS

118

+ W.P.(C) 1511/2021,, CM APPL. 4331/2021(Direction)
CM APPL. 8616/2022(Direction)
MASTER KENIT JHAWAR @ KESHAV Petitioner

Through: Mr. Rahul Malhotra, Mr. Manas Tripathi and Mr. Anshul Gupta, Advocates

versus

UNION OF INDIA & ANR. Respondent

Through: Mr. Sidharth Khatana, Adv. for UOI.
Mr. Tanveer Oberoi, Adv. for AIIMS

119

+ W.P.(C) 1611/2021, CM APPL. 4600/2021(Direction)
LAKSHYA KUMAR GOYAL, 8 YRS OLD, THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH. VIPIN KUMAR

..... Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar Utkarsh and Mr. Manoj Kumar, Advs.

versus

UNION OF INDIA & ANR. Respondent

Through: Ms. Bharati Raju, Adv. for UOI.
Mr. Tanveer Oberoi, Adv. for AIIMS

120

+ W.P.(C) 5315/2020,, CM APPL. 19189/2020(Direction)

MASTER ARNESH SHAW Petitioner

Through: Mr. Rahul Malhotra, Mr. Manas
Tripathi and Mr. Anshul Gupta, Advs.
Mr. Sidharth Luthra, Sr. Adv. with
Mr. Asif Ahmed, Ms. Sanjivani
Pattjoshi, Advs.

versus

UNION OF INDIA & ANR. Respondent

Through: Mr. Ripudaman Bhardwaj, CGSC for
UOI
Mr. Tanveer Oberoi, Adv. for AIIMS

121

+ W.P.(C) 3662/2021, CM APPL. 11103/2021(Stay), CM APPL.
25590/2021(Direction), CM APPL. 32504/2021(14 Days Delay)

PAYEL BHATTACHARYA Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh, Mr. Manoj Kumar, Advs.

versus

UNION OF INDIA & ORS. Respondent

Through: Mr. Ripudaman Bhardwaj, CGSC for
UOI.
Mr. Anuj Aggarwal, ASC, GNCTD
with Ms. Ayushi Bansal, Mr. Sanyam
Suri and Ms. Aishwarya Sharma,
Advs. for R-2.

Mr. Tanveer Oberoi, Adv. for AIIMS

122

+ W.P.(C) 3682/2021, CM APPL. 11153/2021(Direction)

HARSHIT SONI, 16 YEARS OLD, THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SH. TIKAM CHAND SONI

..... Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.

versus

UNION OF INDIA & ANR. Respondent
Through: Mr. T. P. Singh, Adv. for UOI
Mr. Tanveer Oberoi, Adv. for AIIMS

123

+ W.P.(C) 3689/2021, CM APPL. 11179/2021(Direction)
DHANANJAY BHARDWAJ, 11 YEARS OLD, THROUGH HIS
NEXT FRIEND AND NATURAL FATHER SH. AMIT KUMAR
..... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh, Mr. Manoj Kumar, Adv.

versus

UNION OF INDIA & ANR. Respondent
Through: Mr. Sanjeev Uniyal, Mr. Dhawal
Uniyal, and Mr. Sachin Chandela,
Adv. for UOI.
Mr. Tanveer Oberoi, Adv. for AIIMS

124

+ W.P.(C) 3706/2021, CM APPL. 11229/2021(Direction)
KHUSHWANT BHARDWAJ, 7 YEARS OLD, THROUGH HIS
NEXT FRIEND AND NATURAL FATHER SH. NIKHIL
BHARDWAJ
..... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Adv.

versus

UNION OF INDIA & ANR. Respondent
Through: Mr. Sanjib Kumar Mohanty with Mr.
Subesh Kumar Sahoo, Adv. for R-1.
Mr. Tanveer Oberoi, Adv. for AIIMS

125

+ W.P.(C) 3707/2021, CM APPL. 11230/2021(Direction)
AARAV GARG, 5 YEARS OLD, THROUGH HIS NEXT FRIEND
AND NATURAL FATHER SH. VIVEK
..... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Adv.

versus

UNION OF INDIA & ANR. Respondent
Through: Mr. Sidharth Khatana, Adv. for UOI
Mr. Tanveer Oberoi, Adv. for AIIMS

126

+ W.P.(C) 3729/2021, CM APPL. 11269/2021(Direction)
MANISH, 8 YEARS OLD, THROUGH HIS NEXT FRIEND AND
NATURAL FATHER SH. PHOOL CHAND JAT & ANR.
..... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.
versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Tanveer Oberoi, Adv. for AIIMS

127

+ W.P.(C) 3737/2021, CM APPL. 11277/2021(Direction)
SHOURYA MARU, 7 YEARS OLD, THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SH. KAMAL KUMAR
MARU
..... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.
versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Ranvir Singh, CGSC
Mr. Tanveer Oberoi, Adv. for AIIMS

128

+ W.P.(C) 3859/2021, CM APPL. 11647/2021(Direction)
SIDDHARTH SWARNKAR, 9 YEARS OLD, THROUGH HIS
NEXT FRIEND AND NATURAL FATHER SH. DINESH KUMAR
SWARNKAR
..... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.
versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Tanveer Oberoi, Adv. for AIIMS

129

+ W.P.(C) 4045/2021, CM APPL. 12213/2021(Direction)
UTKARSH INDRAJIT PAWAR, 10 YEARS OLD, THROUGH HIS
NEXT FRIEND AND NATURAL FATHER SH. INDRAJIT
DAMAR PAWAR
..... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.

versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Harish Kumar Garg and Ms.
Falguni Rai, Advs. for R-1.
Mr. Tanveer Oberoi, Adv. for AIIMS

130

+ W.P.(C) 4067/2021, CM APPL. 12306/2021(Direction)
ANSHU, 10 YEARS OLD, THROUGH HIS NEXT FRIEND AND
NATURAL FATHER SH. NARENDRA KUMAR YADAV
..... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.

versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Sanjeev Sabharwal, Adv. for UOI
Mr. Tanveer Oberoi, Adv. for AIIMS

131

+ W.P.(C) 4259/2021, CM APPL. 12948/2021(Direction)
ISHAAN, 10 YEARS OLD, THROUGH HIS NEXT FRIEND AND
NATURAL FATHER SH. RAJVIR SINGH Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.

versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Tanveer Oberoi, Adv. for AIIMS

132

+ W.P.(C) 4304/2021, CM APPL. 13108/2021(Direction)
TANAV HANDOO, 6 YEARS OLD, THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SH. AMIT HANDOO
..... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.

versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Satya Ranjan Swain, Sr. Panel
Counsel with Mr. Kautilya Birat,
Adv. for UOI.
Mr. Tanveer Oberoi, Adv. for AIIMS

133

+ W.P.(C) 4551/2021, CM APPL. 13949/2021(Direction)
SHAURYA DAHIYA, 7 YEARS OLD, THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SH. SATBIR DAHIYA
..... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.
versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Avnish Singh, Adv. for UOI.
Mr. Tanveer Oberoi, Adv. for AIIMS

134

+ W.P.(C) 4812/2021, CM APPL. 14844/2021(Direction)
NIKHIL YOGENDERSINGH CHOUDARY, 17 YEARS OLD,
THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH.
YOGENDERSINGH P CHOUDARY Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.
versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Ranvir Singh, CGSC for UOI
Mr. Tanveer Oberoi, Adv. for AIIMS

135

+ W.P.(C) 5394/2021, CM APPL. 16683/2021(Direction)
UDAYVEER SINGH GULERIA, 7 YEARS OLD, THROUGH HIS
NEXT FRIEND AND NATURAL FATHER SH. RAMESH
GULERIA Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.
versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Tanveer Oberoi, Adv. for AIIMS

136

+ W.P.(C) 5395/2021, CM APPL. 16686/2021(Direction)
MASTER AYUSHMAN CHATURVEDI Petitioner
Through: Mr. Gautam Barnwal, Advocate
versus
UNION OF INDIA & ORS. Respondent

Through: Mr. Niraj Kumar, Advocate for R-1.
Mr. Tanveer Oberoi, Adv. for AIIMS
Mr. G.D. Sharma, Adv. for R-4.

137

+ W.P.(C) 9684/2021

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

Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.

versus

UNION OF INDIA & ORS. Respondent

Through: Mr. Tanveer Oberoi, Adv. for AIIMS

138

+ W.P.(C) 14317/2021, CM APPL. 45148/2021(Direction)

SHREYANSH AARAV, 11 YEARS OLD, THROUGH HIS NEXT
FRIEND AND NATURAL MOTHER SMT. KANCHAN KAMINI
..... Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.

versus

UNION OF INDIA & ANR. Respondent

Through: Mr. Ripudaman Bhardwaj, CGSC for
UOI

Mr. Tanveer Oberoi, Adv. for AIIMS

139

+ W.P.(C) 2943/2020, CM APPL. 6633/2022(Direction)

ALISHBA KHAN Petitioner

Through: Mr. Rahul Malhotra, Mr. Manas
Tripathi and Mr. Anshul Gupta, Advs.

versus

UNION OF INDIA AND ORS. Respondent

Through: Mr. Amit Mahajan, CGSC and Ms.
Vidhi Jain, Advocate for UOI
Mr. Tanveer Oberoi, Adv. for AIIMS
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Raghav
Anand, Adv.

Mr. Chetan Sharma, ASG with Mr. Ripu Daman Bhardwaj, CGSC, Mr. Amit Gupta, Mr. Vinay Yadav, Mr. R.V. Prabhat, Mr. Sahaj Garg, Mr. Rishav Dubey, Mr. Ajay Dignpaul, CGSC Mr. Vijay Joshi, Advs. for UOI.

Mr. Anuj Agarwal, ASC with Ms. Ayushi Bansal, Mr. Sanyam Suri, Ms. Aishwarya Sharma, Advs. for R-2 and R-4.

140

+ W.P.(C) 10782/2020, CM APPL. 33828/2020(Direction)
AVIRAJ GARG, AGE 4 YEARS, THROUGH HIS NEXT FRIEND
AND NATURAL FATHER SH. ABHINAV GARG..... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.
versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Tanveer Oberoi, Adv. for AIIMS

CORAM:

HON'BLE MR. JUSTICE YASHWANT VARMA

ORDER

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12.04.2022

W.P.(C) 11610/2017, CM APPL. 27637/2018 (Direction), W.P.(C) 1182/2022, CM APPL. 3442/2022 (Direction), W.P.(C) 322/2021, CM APPL. 812/2021 (Direction), W.P.(C) 1491/2021, CM APPL. 4291/2021 (Direction), CM APPL. 8671/2022 (Direction), W.P.(C) 1511/2021, CM APPL. 4331/2021(Direction), CM APPL. 8616/2022(Direction), W.P.(C) 1611/2021, CM APPL. 4600/2021(Direction), W.P.(C) 5315/2020, CM APPL. 19189/2020 (Direction), W.P.(C) 3662/2021, CM APPL. 11103/2021 (Stay), CM APPL. 25590/2021 (Direction), CM APPL. 32504/2021 (14 Days Delay), W.P.(C) 3682/2021, CM APPL. 11153/2021 (Direction), W.P.(C) 3689/2021, CM APPL. 11179/2021 (Direction), W.P.(C) 3706/2021, CM APPL. 11229/2021 (Direction), W.P.(C) 3707/2021, CM APPL. 11230/2021 (Direction), W.P.(C) 3729/2021, CM APPL. 11269/2021 (Direction), W.P.(C) 3737/2021, CM APPL. 11277/2021 (Direction), W.P.(C) 3859/2021, CM APPL. 11647/2021

(Direction), W.P.(C) 4045/2021, CM APPL. 12213/2021 (Direction), W.P.(C) 4067/2021, CM APPL. 12306/2021 (Direction), W.P.(C) 4259/2021, CM APPL. 12948/2021 (Direction), W.P.(C) 4304/2021, CM APPL. 13108/2021 (Direction), W.P.(C) 4551/2021, CM APPL. 13949/2021 (Direction), W.P.(C) 4812/2021, CM APPL. 14844/2021 (Direction), W.P.(C) 5394/2021, CM APPL. 16683/2021(Direction), W.P.(C) 5395/2021, CM APPL. 16686/2021(Direction), W.P.(C) 9684/2021, W.P.(C) 14317/2021, CM APPL. 45148/2021(Direction), W.P.(C) 2943/2020, CM APPL. 6633/2022(Direction), W.P.(C) 10782/2020, CM APPL. 33828/2020(Direction)

1. This batch of petitions has been taken up for review pursuant to the earlier orders of the Court of 14 December 2021 and 1 February 2022. The learned Amicus has placed for the consideration of the Court a detailed chart setting out the rare diseases which afflict the individual children, the recommendations made in respect of each individual child by the Committee for Rare Diseases as constituted by AIIMS and the status of treatment.

2. Taking first the disease of Duchenne Muscular Dystrophy (DMD), the Court notes that the petitioners in W.P.(C) 5315/2020, 10782/2020, 322/2021, 1611/2021, 3682/2021, 3689/2021, 3706/2021, 3707/2021, 3729/2021, 3737/2021, 3859/2021, 4045/2021, 4067/2021, 4259/2021, 4304/2021, 4551/2021, 5394/2021, 4812/2021, 5395/2021, 14317/2021 have already been assessed by the Committee for Rare Diseases and have been recommended for treatment. This is also duly noted in the affidavit of 26 October 2021 which has been filed by AIIMS in these proceedings. Learned counsel appearing for AIIMS however points out that till date no demands have been placed with respect to the release of requisite funds upon the Union in respect of this category in light of the decision of the Central Technical Committee which functions at the level of the Ministry of Health. Reference in this regard is made to the Minutes of 11 March 2022.

The Court notes that AIIMS appears to have harboured the impression that the line of treatment as suggested by the Committee for Rare Disease had not found acceptance of the Central Technical Committee for reasons recorded in its decision of 11 March 2022.

However this would appear to be inaccurate when one bears the following observations as appearing in the Minutes of the Meeting held by that Committee which are quoted hereinbelow:-

- “The group was of the opinion that as of date, scientific data is not sufficiently robust to suggest meaningful clinical improvement by the newer exon skipping based dystrophin protein restoration therapies or nonsense mutation bypass though slower progression as compared to historical controls has been documented. Literature is based on small sample size studies, has not documented stoppage of progression of disease in short or long term use with these therapies. Many of them are very recently approved drugs with very limited literature (all are FDA approved, except Ataluren which is European Medical agency approved).
- There was a detailed discussion about the available newer therapies for DMD. The members were concerned about the patients and their families, and the morbidity associated with this progressive disease. At the same time there was a concern raised by most members about the paucity of data regarding long term clinically meaningful improvement or documented stoppage of disease progression as only few years of increased ambulation was observed based on most of current published evidence. Members were of the opinion that keeping the patient perspective in mind and approval of these drugs by the FDA/EU, our patients should not be deprived of the drugs being recommended in most of the countries in the developed world. However the prohibitive cost of INR 6 to 8 crore annually for a 30 kg child and the lack of clinically meaningful response reported till date makes the cost effectiveness of these newer therapies questionable.”

3. It is evident from a perusal of the aforesaid extracts of the minutes of the meeting of the Committee that the particular drug which had been recommended for administration stands duly approved by the regulatory authorities both in the European Union (EU) as well as by the Food and Drug Administration (FDA) of the United States of America. The Central Technical Committee appears to have only raised the issue of whether the proposed treatment would be cost effective. The observation of those therapies being “*questionable*” thus cannot be read or understood out of context. Additionally the Court notes that the aforesaid observations were prefaced by the said Committee itself noting that since those drugs were being administered across the globe and in other regulated environments, patients in India should not be deprived of the drug. In view of the above, the purport of the resolution of the Central Technical Committee does not appear to have been correctly appreciated by AIIMS.

4. In that view of the matter, let AIIMS place its demand with respect to release of requisite funds which would meet the needs for the treatment of patients suffering from DMD. The Union shall take those demands into consideration and place its stand on the record of these proceedings by way of an affidavit to be filed on or before the next date fixed.

5. The Court next takes notice of the two intervenors in CM No. 42378/2019 (allowed vide order dated 11 October 2019) who are yet to be assessed for treatment and are stated to be afflicted by Spinal Muscular Atrophy (SMA).

6. In view of the above, let the Committee for Rare Diseases of AIIMS duly undertake an assessment of these two intervenors and furnish its recommendations in these proceedings by way of an affidavit to be tendered

by a responsible officer.

7. The Court's attention has also been drawn to the case of the petitioners in W.P.(C) 1491/2021 and W.P.(C) 1511/2021. Admittedly treatment is being administered to the petitioner in W.P.(C) 1511/2021 based on funds which were raised by the parents of the child. Insofar as the petitioner in W.P.(C) 1491/2021 is concerned, treatment has not commenced apparently because of funds having not been procured for the purposes of commencement of treatment. If that be so and since the treatment with respect to this petitioner has also been duly recommended by the Committee for Rare Diseases, AIIMS is directed to place a demand with respect to release of funds that may be required for this patient also upon the Union. The Union shall submit its responses on the demands which shall now be placed by AIIMS on or before the next date fixed.

8. Learned counsel appearing for the Union has on instructions stated that it has decided to question the orders dated 14 December 2021 and 01 February, 2022 by way of a Special Leave Petition before the Supreme Court. The Court is apprised that presently the said Special Leave Petition is lying in defect. Let the Court be apprised the outcome of the said petition on the next date fixed.

9. List again on 29.04.2022 at 2:15 pm.

YASHWANT VARMA, J.

APRIL 12, 2022

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