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

+ **CONT.CAS(C) 415/2022 & CM APPL. 18280/2022**
MASTER MEDHANSH JHAWAR @ MADHAV THROUGH HIS
NATURAL GUARDIAN Petitioner
Through: **Mr.Rahul Malhotra and Mr.Anshul Gupta, Advs.**

versus

RAJESH BHUSHAN & ORS. Respondents
Through: **Mr.Tanveer Oberoi, Adv. for AIIMS.**

8

+ **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.**
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan Poddar Adv.

versus

UNION OF INDIA & ORS. Respondents
Through: **Mr. Sanjeev Uniyal, Mr. Dhawal Uniyal, Mr. Sachin Chandela, Advs.**
for UOI.
Mr. Rishikesh Kumar, ASC, GNCTD
with **Ms. Sheenu Priya and Mr.**
Sudhir Shukla, Advs. for R-4.

9

+ **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.**

Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

versus
UNION OF INDIA & ANR. Respondent
Through: Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.
Mr. Ajay Digpaul, CGSC, Mr. Kamal Digpaul, Adv. for UOI.

10

+ 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, Advs.
Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

versus
UNION OF INDIA & ANR. Respondent
Through: counsel appearance not given.

11

+ 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, Advs.
Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Ghanshyam Mishra, Mr. Rishav Dubey and Mr. Sameer Sharma, Advs.

for UOI.

12

+ 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.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus

UNION OF INDIA & ANR.

..... Respondent

Through: Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.
Mrs.Bharathi Raju, Sr. Panel Counsel
for R-1.

13

+ 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.Prateek Dhanda and Mr.Asif
Ahmed, Advs.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus

UNION OF INDIA & ANR.

..... Respondent

Through: Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.
Mr.Ripu Daman Bhardwaj, CGSC
with Mr.Kushagra Kumar, Adv. for
UOI.

14

+ 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. Shivam, Mr. Aditya Chatterjee,
Mr. Abhishek Singh, Advs.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus

UNION OF INDIA & ORS.

..... Respondent

Through: Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

Mr. Anuj Agarwal, ASC with
Ms. Ayushi Bansal, Mr. Sanyam Suri,
Ms. Aishwarya Sharma, Advs. for R-2
Mr. Ripu Daman Bhardwaj, CGSC
with Mr. Kushagra Kumar, Adv. for
UOI.

15

+ 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.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus

UNION OF INDIA & ANR.

..... Respondent

Through: Mr. T. P. Singh, Sr. central govt.
counsel with Mr. R. Singh, Adv.

16

+ 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, Advs.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus
UNION OF INDIA & ANR.

..... Respondent

Through:
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.
Mr. Sanjeev Uniyal, Mr. Dhawal
Uniyal, and Mr. Sachin Chandela,
Advs. for UOI.

17

+ 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, Advs.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus
UNION OF INDIA & ANR.

..... Respondent

Through:
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.
Mr. Sanjib Kumar Mohanty, Sr. panel
central govt. counsel with Mr. Subesh
Kumar Sahoo, Adv. for R-1.

18

+ 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, Advs.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus

UNION OF INDIA & ANR. Respondents
Through: Mr. Sidharth Khatana, Adv. for R-1.

19

+ 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.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus

UNION OF INDIA & ANR. Respondent
Through: counsel appearance not given.

20

+ 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.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus
UNION OF INDIA & ANR. Respondent
Through: Mr.Ranvir Singh, CGSC for UOI.

21

+ 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.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus
UNION OF INDIA & ANR. Respondent
Through: Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

22

+ 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.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus
UNION OF INDIA & ANR. Respondent
Through: Mr.Harish Kumar Garg, Adv. for R-1.

23

+ 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.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus
UNION OF INDIA & ANR. Respondent
Through: Mr. Sanjeev Sabharwal, Sr. govt.
counsel for UOI with Ms. Shruti
Gupta, Adv.

24

+ 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.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus
UNION OF INDIA & ANR. Respondent
Through: Counsel appearance not given.

25

+ W.P.(C) 4304/2021, CM APPL. 13108/2021(Direction)
TANAV HANDOO, 6 YEARS OLD, THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SH. AMIT HANOO Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh and Mr. Manoj Kumar, Advs.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus
UNION OF INDIA & ANR. Respondent

Through: Mr.Satya Ranjan Swain, Sr. Panel Counsel with Mr.Kautilya Birat, Adv. for UOI.

26

+ 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. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

versus

UNION OF INDIA & ANR. Respondent

Through: Mr.Avnish Singh, Sr. central govt. counsel for UOI.

27

+ 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. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

versus

UNION OF INDIA & ANR. Respondent

Through: Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.
Mr.Ranvir Singh, CGSC for UOI.

28

+ 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. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

versus

UNION OF INDIA & ANR.

..... Respondent

Through: Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

29

+ W.P.(C) 5395/2021, CM APPL. 16686/2021(Direction)
MASTER AYUSHMAN CHATURVEDI Petitioner
Through: Mr. Anurag Ojha and Mr. Karan Aggarwal, Advs.
Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

versus

UNION OF INDIA & ORS.

..... Respondent

Through: Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.
Mr. Niraj Kumar, Sr. central govt. counsel with Mr. Farman Ali and Ms. Usha Jamnal, Advs. for R-1.
Ms. Varsha Sharma, Mr. Jawahar Raja, ASC (C) for R-2.
Mr. G. D. Sharma, Adv. for R-4.

30

+ 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.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus
UNION OF INDIA & ORS. Respondent
Through: Mr.Ripu Daman Bhardwaj, CGSC
with Mr.Kushagra Kumar, Adv. for
UOI.
Mr. Tanveer Oberoi, Adv. for AIIMS

31

+ 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.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus
UNION OF INDIA & ANR. Respondent
Through: Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

32

+ 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.
Ms. Shyel Trehan, Amicus Curie [M.
No. 09810163818] with Mr. Rohan
Poddar Adv.

versus
UNION OF INDIA AND ORS. Respondent

Through: Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

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

33

+ 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. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

versus
UNION OF INDIA & ANR. Respondent
Through: Counsel appearance not given.

34

+ 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. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

versus
UNION OF INDIA AND ANR. Respondent
Through: Mr. Vijay Joshi, Sr. panel counsel for R-1.
Mr. Manashwy Jha, Adv. for Mr. Sameer Vashisht, ASC (C) for R-2.
Mr. Saurabh Chauhan and Mr. Varun Jain, Advs. for applicants in CM No. 42378/2019.

Mr.Sameer Vashisht, ASC GNCTD
with Ms. Sanjana Nangia, Adv. for
GNCTD.

CORAM:

HON'BLE MR. JUSTICE YASHWANT VARMA

O R D E R

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01.06.2022

Pursuant to the last orders passed, the recommendations of the AIIMS Expert Committee have been placed on the record in terms of a report dated 30 May 2022. From the chart which stands appended along with that report, the Court notes that insofar as the petitioners in W.P.(C) Nos. 3689/2021, 1611/2021, 4067/2021, 3737/2021 & 14317/2021 are concerned, the Expert Committee has opined that the administration of the drug may help in attenuating the decline in cardiac and respiratory as well as ambulatory functions. Although the Committee has further gone on to observe that there is presently no evidence which may suggest that the administration of the drug would stop the disease from progressing and that long term outcomes are unknown, the Court is of the opinion that treatment to the aforesaid patients would not merit being deferred on the ground that long term clinical trial studies are not available or that adequate evidentiary material does not exist. The Court bears in mind that insofar as these rare diseases are concerned, there is admittedly a dearth of authoritative research material which may indicate or establish the long term outcome of the treatment protocols which are presently being followed. That, however, should not detract from the right of the patients to undergo the treatment options which are currently available and are being administered to similar patients across the globe even if they be viewed as experimental therapies.

The Court is also informed that on 19 May 2022 the Government of

India has issued an Office Memorandum in terms of which it has been provided that financial support of upto Rs. 50 lakhs shall be provided to patients suffering from any category of rare diseases. The said Office Memorandum is extracted hereinbelow:-

“File No: W-11037/40/2022-Grants (RD)
Government of India
Ministry of Health & Family Welfare
(Rare Diseases Cell)

Nirman Bhawan, New Delhi
Dated: 19/5/2022

OFFICE MEMORANDUM

The undersigned is directed to state that the following provision envisaged under Para 10(i) of National Policy for Rare Diseases (NPRD), 2021:

"Financial support upto Rs. 20 lakh under the Umbrella Scheme of Rashtriya Arogaya Nidhi shall be provided by the Central Government for treatment, of those rare diseases that require a one-time treatment (diseases listed under Group 1). Beneficiaries for such financial assistance would not be limited to BPL families, but extended to about 40% of the population, who are eligible as per norms of Pradhan Mantri Jan Arogya Yojana, for their treatment in Government tertiary hospitals only."

may be treated as replaced with the following:

"Financial support upto Rs. 50 lakhs shall be provided to the patients suffering from any category of the Rare Diseases. The financial support will be provided to the patients for the treatment in any of the Centre of Excellence (CoE) mentioned in NPRD-2021, outside the Umbrella Scheme of Rashtriya Arogaya Nidhi."

2. All other provisions of the policy will remain unchanged.
3. These amendments come into effect from the date of issue of this Office Memorandum.
4. The guidelines/procedure for providing financial assistance to the patients as per amended provisions are being finalized. However, till the finalization of guidelines and in order to provide uninterrupted and enhanced financial assistance i.e. upto Rs. 50 lakhs to the patients of rare diseases irrespective of category of disease, funds may continued to be granted from the current budget head of Umbrella Scheme of Rashtriya Arogya Nidhi (RAN).
5. This Issues with the approval of the competent authority.

(Manish Raj)
Under Secretary to the Govt. of India
Tel. 011-23062068”

The amendments as introduced would indicate that the financial support which was spelt at Rs. 20 lakhs and which was in turn dealing with a one-time treatment of diseases listed under Group 1 has been done away with. In view of the aforesaid and the communication of 25 May 2022, let AIIMS forward its proposal for commencement of treatment to the petitioners aforesaid to the competent officer in the Ministry of Health and Family Welfare, Government of India.

The Court further directs the competent authority in the Department of Biotechnology which stands arrayed as a party respondent in the present proceedings to further explore and file a response in the present writ petition disclosing other generic norms of treatment that may be under development

and may warrant consideration in respect of children suffering from rare diseases in this batch of writ petitions.

The Court also requests the learned Amicus Curiae to contact Dr. Apurba Ghosh and Mr. Arun Shastry and to request them to attend to the proceedings of this writ petition on the next date or to submit their views on the record of this writ petition so that further directions may be formulated.

List on 05.08.2022.

YASHWANT VARMA, J.

JUNE 01, 2022
SU