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* **IN THE HIGH COURT OF DELHI AT NEW DELHI**
Date of Decision: 15th May, 2023

(55)

+ **W.P.(C) 5315/2020 & CM APPL. 19189/2020, 4237/2023**
MASTER ARNESH SHAW Petitioner
Through: Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.
Mr. Asif Ahmed, Advocate.

versus

UNION OF INDIA & ANR. Respondents
Through: Mr. Kirtiman Singh, CGSC, Ms. Vidhi
Jain, Advocate for UOI.
Mr. Ripudaman Bhardwaj CGSC with
Mr. Kushagra Kumar Adv. for UOI.
Mr. Tanveer Oberoi, Adv. for
(AIIMS).
Mr Dharmender Verma Adv., Mr.
Vishal Singh Adv., Mr. Shantanu Garg
Advocate for BIRAC with AR Mr.
Amit Kumar.

(54)

+ **WITH**
CONT.CAS(C) 415/2022 & CM APPL. 18280/2022
MASTER MEDHANSH JHAWAR @ MADHAV THROUGH HIS
NATURAL GUARDIAN Petitioner
Through: Mr. Rahul Malhotra & Ms. Shruti
Gupta, Advocates.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.
(M: 6370344354)

versus

RAJESH BHUSHAN & ORS. Respondent
Through: Mr. Kirtiman Singh, CGSC, Ms. Vidhi
Jain, Advocate for UOI.
Mr. Divyam Nandrajog, Panel
Counsel, GNCTD with Mr. Mayank
Kamra, Adv. for R-2.
Mr. Tanveer Oberoi for AIIMS

(M:9958935556) and Mr. Jaswinder Singh,
Advocate (M:9811232066)
Dr. Shefali Gulati in person.

(56)

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WITH
W.P.(C) 11610/2017 & CM APPL. 27637/2018, 44016/2022
FSMA INDIA CHARITABLE TRUST Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh, Ms. Nishtha Jain & Mr.
Manoj Kumar, Advs.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA AND ANR. Respondents
Through: Mr. Sameer Vashisht, ASC (Civil),
GNCTD and Mr. Vanshay Kaul, Adv.
for R-2.
Mr. Vijay Joshi, Sr. Panel Counsel for
UOI.
Mr. Tanveer Oberoi, Adv. for
(AIIMS).
Mr. Saurabh Chauhan & Mr. Varun
Jain, Advocates for intervenors.

(57)

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WITH
**W.P.(C) 2943/2020 & CM APPLs. 10227/2020, 6633/2022,
7534/2023**
ALISHBA KHAN Petitioner

Through: Mr. Rahul Malhotra & Ms. Shruti
Gupta, Advocates.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA AND ORS. Respondents
Through: Mr. Anuj Aggarwal, ASC, GNCTD,
Ms. Ayushi Bansal, Ms. Arshya Singh,
Advocates for R-2 and 4
(M:9891363718).
Mr. Tanveer Oberoi, Adv. for

(AIIMS).

(58)

WITH

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W.P.(C) 10782/2020 & CM APPL. 33828/2020AVIRAJ GARG, AGE 4 YEARS, THROUGH HIS NEXT FRIEND
AND NATURAL FATHER SH. ABHINAV GARG..... PetitionerThrough: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh & Mr. Manoj Kumar, Advs.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR. Respondents

Through: Ms. Amrita Prakash, CGSC and Mr.
Vishal Ashwani Mehta, Advocates
(M:9818667963).
Mr. Tanveer Oberoi, Adv.

(59)

WITH

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W.P.(C) 322/2021 & CM APPL. 812/2021KESHAV SHARMA AGE 12 YEARS THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SANJEEV
KUMAR PetitionerThrough: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh & Mr. Manoj Kumar, Advs.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR. Respondents

Through: Mr. Ajay Diggpaul and Mr. Kamal
Diggpaul with Ms. Swati Kwatra,
Advocates for UOI.
Mr. Tanveer Oberoi, Adv. for
(AIIMS).

(60)

WITH

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W.P.(C) 1491/2021 & CM APPLs. 4291/2021, 8671/2022

MASTER MEDHANSH JHAWAR @ MADHAV Petitioner

Through: Mr. Rahul Malhotra & Ms. Shruti
Gupta, Advocates.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

- versus
UNION OF INDIA & ANR. Respondents
Through: Mr. Kirtiman Singh & Ms. Vidhi Jain,
Advocates (M: 9999359235)
Mr. Tanveer Oberoi, Adv. for
(AIIMS).
- (61) WITH
+ **W.P.(C) 1511/2021 & CM APPL. 4331/2021, 8616/2022**
MASTER KENIT JHAWAR @ KESHAV Petitioner
Through: Mr. Rahul Malhotra & Ms. Shruti
Gupta, Advocates.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.
- versus
UNION OF INDIA & ANR. Respondents
Through: Mr. Rishabh Sahu, Central Govt Sr.
Counsel with Mr Sameer Sharma,
Adv. for UOI.
Mr. Ghanshyam Mishra, Advocate
with Mr. Babli Chauhan, Adv. for
R-1. (M: 9899794006)
Mr. Tanveer Oberoi, Adv. for
(AIIMS).
- (62) WITH
+ **W.P.(C) 1611/2021 & CM APPL. 4600/2021**
LAKSHYA KUMAR GOYAL, 8 YRS OLD, THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SH. VIPIN
KUMAR. ... Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh & Mr. Manoj Kumar, Advs.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.
- versus
UNION OF INDIA & ANR. Respondents
Through: Mr. Bharathi Raju, Sr. Panel Counsel
for UOI. (M:9868895906)
Mr. Tanveer Oberoi, Adv. for
(AIIMS).

(63) WITH
 + **W.P.(C) 3662/2021 & CM APPLs. 11103/2021, 25590/2021, 32504/2021**
 PAYEL BHATTACHARYA Petitioner
 Through: Mr. Aditya Chatterjee and Mr. Ishaan Karki, Advocates.
 Ms. Shyel Trehan, Mr. Rohan Poddar & Ms. Shivalika Rudrabatla, Advs.

versus
 UNION OF INDIA & ORS. Respondents
 Through: Mr. Anuj Aggarwal, ASC, GNCTD, Ms. Ayushi Bansal, and Ms. Arshya Singh, Advocates for R-2 (M:9891363718).
 Mr. Ripudaman Bhardwaj CGSC with Mr. Kushagra Kumar Adv. for UOI.
 Mr. Tanveer Oberoi, Adv. for (AIIMS).

(64) WITH
 + **W.P.(C) 3682/2021 & CM APPL. 11153/2021**
 HARSHIT SONI, 16 YEARS OLD, THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH. TIKAM CHAND SONI Petitioner
 Through: Mr. Ashok Agarwal, Mr. Kumar Utkarsh & Mr. Manoj Kumar, Advs.
 Mr. Rahul Malhotra & Ms. Shruti Gupta, Advocates.
 Ms. Shyel Trehan, Mr. Rohan Poddar & Ms. Shivalika Rudrabatla, Advs.

versus
 UNION OF INDIA & ANR. Respondents
 Through: Mr. T.P. Singh, Sr. Central Govt. Counsel for R-1 (M:9971579687).
 Mr. Tanveer Oberoi, Adv. for (AIIMS).

(65) WITH
 + **W.P.(C) 3689/2021 & CM APPL.11179/2021**
 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, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR.

..... Respondents

Through: Mr. Sanjeev Uniyal and Mr. Dhawal
Uniyal, Advs for R-1
(M:9560806614).
Mr. Tanveer Oberoi, Adv. for
(AIIMS).

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WITH

W.P.(C) 3706/2021 & CM APPL. 11229/2021

KHUSHWANT BHARDWAJ, 7 YEARS OLD,
THROUGH HIS NEXT FRIEND AND NATURAL
FATHER SH. NIKHIL BHARDWAJ

..... Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh & Mr. Manoj Kumar, Advs.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR.

..... Respondents

Through: Mr. Sanjib Kumar Mohanty, Sr. Panel
Counsel with Mr. Subesh K. Sahoo,
Adv. for R-1.
Mr. Tanveer Oberoi, Adv. for
(AIIMS).

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WITH

W.P. (C) 3707/2021 & CM APPL. 11230/2021

AARAV GARG, 5 YEARS OLD, THROUGH HIS
NEXT FRIEND AND NATURAL FATHER SH.
VIVEK

..... Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh & Mr. Manoj Kumar, Advs.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus
 UNION OF INDIA & ANR. Respondents
 Through: Mr. Siddharth Khatana, Advocate for
 UOI. (M:9811132326)
 Mr. Tanveer Oberoi, Adv. for
 (AIIMS).

(68) WITH
 + **W.P.(C) 3729/2021 & CM APPL. 11269/2021**
 MANISH, 8 YEARS OLD, THROUGH HIS NEXT FRIEND AND
 NATURAL FATHER SH. PHOOL CHAND JAT &
 ANR Petitioners
 Through: Mr. Ashok Agarwal, Mr. Kumar
 Utkarsh & Mr. Manoj Kumar, Advs.
 Ms. Shyel Trehan, Mr. Rohan Poddar
 & Ms. Shivalika Rudrabatla, Advs.

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

(69) WITH
 + **W.P.(C) 3737/2021 & CM APPL. 11277/2021**
 SHOURYA MARU, 7 YEARS OLD,
 THROUGH HIS NEXT FRIEND AND NATURAL
 FATHER SH. KAMAL KUMAR MARU Petitioner
 Through: Mr. Ashok Agarwal, Mr. Kumar
 Utkarsh & Mr. Manoj Kumar, Advs.
 Ms. Shyel Trehan, Mr. Rohan Poddar
 & Ms. Shivalika Rudrabatla, Advs.

versus
 UNION OF INDIA & ANR. Respondents
 Through: Mr. Ranvir Singh (CGSC) for R-1.
 (M:9818071061)
 Mr. Tanveer Oberoi, Adv. for
 (AIIMS).

(70) WITH
 + **W.P.(C) 3859/2021 & CM APPL. 11647/2021**
 SIDDHARTH SWARNKAR, 9 YEARS OLD,
 THROUGH HIS NEXT FRIEND AND NATURAL

FATHER SH. DINESH KUMAR SWARNKAR Petitioner
Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh & Mr. Manoj Kumar, Advs.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR. Respondents
Through: Mr. Anuj Aggarwal, ASC, GNCTD
with Ms. Ayushi Bansal, Mr. Sanyam
Suri and Ms. Arshya Singh Advocates
for R-1 to 5 (M:9891363718).
Mr. Tanveer Oberoi, Adv. for
(AIIMS).

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WITH

W.P.(C) 4045/2021 & CM APPL. 12213/2021

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 & Mr. Manoj Kumar, Advs.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR. Respondents
Through: Mr. Sanjeev Sabharwal, Sr. Panel
Counsel with Ms. Shweta, Advocate
for UOI.
Mr. Harish Kumar Garg and Ms.
Khushboo Sharma, Advocates for UOI
(M:9810150029).
Mr. Tanveer Oberoi, Adv. for
(AIIMS).

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WITH

W.P.(C) 4067/2021 & CM APPL. 12306/2021

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

Through: Mr. Ashok Agarwal, Mr. Kumar Utkarsh & Mr. Manoj Kumar, Advs. Ms. Shyel Trehan, Mr. Rohan Poddar & Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR.

..... Respondents

Through: Mr. Tanveer Oberoi, Adv. for (AIIMS).

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WITH

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W.P.(C) 4259/2021 & CM APPL. 12948/2021

ISHAAN, 10 YEARS OLD, THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH. RAJVIR SINGH Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar Utkarsh & Mr. Manoj Kumar, Advs. Ms. Shyel Trehan, Mr. Rohan Poddar & Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR.

..... Respondent

Through: Mr. Tanveer Oberoi, Adv. for (AIIMS).

Mr. Ripudam Bhardwaj, CGSC with Mr. Vinod Tiwari, Adv. for R-1 & 3.

(74)

WITH

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W.P.(C) 4304/2021 & CM APPL. 13108/2021

TANAV HANDOO, 6 YEARS OLD, THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH. AMIT HANDOO Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar Utkarsh & Mr. Manoj Kumar, Advs. Ms. Shyel Trehan, Mr. Rohan Poddar & Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR.

..... Respondents

Through: Mr. Satya Ranjan, (Sr. Panal Counsel) with Mr. Kautilya Birat, Advs for UOI. Mr. Tanveer Oberoi, Adv. for (AIIMS).

(75)

WITH

+ **W.P.(C) 4551/2021 & CM APPL. 13949/2021**
 SHAURYA DAHIYA, 7 YEARS OLD, THROUGH HIS NEXT
 FRIEND AND NATURAL FATHER SH. SATBIR
 DAHIYA Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
 Utkarsh & Mr. Manoj Kumar, Advs.
 Ms. Shyel Trehan, Mr. Rohan Poddar
 & Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR. Respondents

Through: Mr. Avnish Singh, (SCGC) and Ms.
 Pushpalata Singh, Advocate.
 (M:8826437138)
 Mr. Tanveer Oberoi, Adv. for
 (AIIMS).

(76)

WITH

+ **W.P.(C) 4812/2021 & CM APPL. 14844/2021**
 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 & Mr. Manoj Kumar, Advs.
 Ms. Shyel Trehan, Mr. Rohan Poddar
 & Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR. Respondents

Through: Mr. Ranvir Singh (CGSC) for R-1.
 Mr. Tanveer Oberoi, Adv. for
 (AIIMS).

(77)

WITH

+ **W.P.(C) 5394/2021 & CM APPL. 16683/2021**
 UDAYVEER SINGH GULERIA, 7 YEARS OLD,
 THROUGH HIS NEXT FRIEND AND NATURAL FATHER
 SH. RAMESH GULERIA Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
 Utkarsh & Mr. Manoj Kumar, Advs.
 Ms. Shyel Trehan, Mr. Rohan Poddar
 & Ms. Shivalika Rudrabatla, Advs.

- versus
UNION OF INDIA & ANR. Respondents
Through: Mr. Tanveer Oberoi, Adv. for
(AIIMS).
- (78) WITH
+ **W.P.(C) 5395/2021 & CM APPL. 16686/2021**
MASTER AYUSHMAN CHATURVEDI Petitioner
Through: Mr. Deepak Somani, Advocate.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.
- versus
UNION OF INDIA & ORS. Respondents
Through: Mr. Niraj Kumar, Sr. Central Govt.
Counsel for UOI.
Ms. Varsha Sharma for Mr. Jawahar
Raja, ASC(C), GNCTD.
Mr. Tanveer Oberoi, Adv. for
(AIIMS).
- (79) WITH
+ **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 & Mr. Manoj Kumar, Advs.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.
- versus
UNION OF INDIA & ORS. Respondents
Through: Mr. Divyam Nandrajog, Panel
Counsel, GNCTD with Mr. Mayank
Kamra, Adv.
Mr. Tanveer Oberoi, Adv. for
(AIIMS).
- (80) WITH
+ **W.P.(C) 14317/2021 & CM APPL. 45148/2021, 14521/2023**
SHREYANSH AARAV, 11 YEARS OLD, THROUGH HIS NEXT
FRIEND AND NATURAL MOTHER SMT. KANCHAN

KAMINI Petitioner
 Through: Mr. Ashok Agarwal, Mr. Kumar
 Utkarsh & Mr. Manoj Kumar, Advs.
 Ms. Shyel Trehan, Mr. Rohan Poddar
 & Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR. Respondents
 Through: Mr. Ripudaman Bhardwaj CGSC with
 Mr. Kushagra Kumar Adv. for UOI.
 Mr. Tanveer Oberoi, Adv. for
 (AIIMS).

(81)

WITH

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W.P.(C) 1182/2022 & CM APPL. 3442/2022
 INSHA MINOR THROUGH HER NEXT FRIEND AND NATURAL
 FATHER SH IRSHAD AHMAD SOFI..... Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
 Utkarsh & Mr. Manoj Kumar, Advs.
 Ms. Shyel Trehan, Mr. Rohan Poddar
 & Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ORS. Respondents
 Through: Mr. Sanjeev Uniyal & Mr. Dhawal
 Uniyal, Advs for R-1.
 (M:9560806614)
 Mr Rishikesh Kumar ASC, GNCTD
 with Ms. Sheenu Priya, Mr Sudhir
 Mr. Sumit Choudhary, Mr. Sudhir
 Kumar Shukla, Mr Mohammed Zaid
 Mr Aditya Raj and Ms. Roshni
 Haldhar, Advs.
 Mr. Tanveer Oberoi, Adv. for
 (AIIMS).

(82)

WITH

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W.P.(C) 1054/2023 and CM APPL. 4164/2023
 MASTER TUSHAR THROUGH HIS NEXT FRIEND AND
 NATURAL FATHER SH. JAI PRAKASH Petitioner

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

Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR.

..... Respondents

Through:

Mr. Kirtiman Singh, CGSC with Ms.
Vidhi Jain, Advocate for UOI.

Mr. Ripudaman Bhardwaj CGSC with
Mr Hardik Bedi GP for UOI.

Mr. Tanveer Oberoi, Adv. for (AIIMS)

(83)

WITH

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W.P.(C) 1079/2023 and CM APPL. 4248/2023

MASTER RUDRA PAWAR THROUGH HIS NEXT FRIEND AND
NATURAL MOTHER SMT. ANU VISHNOI Petitioner

Through:

Mr. Ashok Agarwal, Mr. Kumar
Utkarsh & Mr. Manoj Kumar, Advs.

Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR.

..... Respondents

Through:

Mr. Kirtiman Singh, CGSC with Ms.
Vidhi Jain, Advocate for UOI.

Dr. Nabendu Sekhar Chatterjee, from
ICMR.

Mr. Ripudaman Bhardwaj CGSC with
Mr Hardik Bedi GP for UOI.

Mr. Tanveer Oberoi, Adv. for (AIIMS)

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AND

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W.P.(C) 2614/2023

KARAN, 14 YEARS OLD THROUGH HIS NEXT FRIEND AND
NATURAL FATHER SH. VIJAY KUMAR Petitioner

Through:

Ms. Sonia Sharma, Ms. Neha Chugh,
Mr. Vijay Chandra jha & Mr. Tushant,
Advs.

Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR.

..... Respondents

Through:

Mr. Nitinjya Chaudhry, Sr Panel

Counsel with Mr. Abhishek, GP (M-9810103680).

Mr. Abhishek Khanna, Adv. for R-1.
Mr. Tanveer Oberoi, Adv. for (AIIMS)

(85)

WITH

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W.P.(C) 4495/2023 & CM APPL.17190/2023
PARAS JAIN THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH. SANDEEP JAIN Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar Utkarsh, and Mr. Manoj Kumar, Advocates. (M: 9811101923)

Ms. Shyel Trehan, Mr. Rohan Poddar & Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR. Respondents

Through: Mr. Raj Kumar, Advocate, SPC, UOI.
Mr. Kirtiman Singh, CGSC with Ms. Vidhi Jain, Adv. for UOI.

(86)

WITH

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W.P.(C) 4502/2023 & CM APPL.17238/2023
SHREYANSH VERMA THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH. DHEERAJ KANT VERMA Petitioner

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

Ms. Shyel Trehan, Mr. Rohan Poddar & Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR. Respondents

Through: Mr. Raj Kumar Yadav, Advocate for UOI. (M:9818836222)

Mr. Kirtiman Singh, CGSC with Ms. Vidhi Jain, Adv. for UOI.

(87)

WITH

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W.P.(C) 4526/2023 & CM APPL.17321/2023
MASTER LAKSHYAVED KALISHARAN THROUGH HIS NEXT FRIEND

AND NATURAL MOTHER SHILPA RAMESH Petitioner
 Through: Mr. Ashok Agarwal, Mr. Kumar
 Utkarsh, and Mr. Manoj Kumar,
 Advocates.
 Ms. Shyel Trehan, Mr. Rohan Poddar
 & Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR. Respondents
 Through: Mr. Kirtiman Singh, CGSC with Ms.
 Vidhi Jain, Adv. for UOI.
 Mr. Virender Pratap Singh Charak and
 Ms. Shubhra Parashar Advocates for
 UOI.

(88)

WITH

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W.P.(C) 4535/2023 & CM APPL.17331/2023
 MASTER CHINMAY BARUPAL THROUGH
 HIS NEXT FRIEND AND NATURAL
 FATHER SH. ASHOK KUMAR BARUPAL Petitioner
 Through: Mr. Ashok Agarwal, Mr. Kumar
 Utkarsh, and Mr. Manoj Kumar,
 Advocates.
 Ms. Shyel Trehan, Mr. Rohan Poddar
 & Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR. Respondents
 Through: Mr. Kirtiman Singh, CGSC with Ms.
 Vidhi Jain, Adv. for UOI.
 Ms. Monika Arora (CGSC) , Mr Yash
 Tyagi , Adv.

(89)

WITH

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W.P.(C) 4536/2023 & CM APPL.17333/2023
 MADHAV SHARMA THROUGH HIS
 NEXT FRIEND AND NATURAL
 FATHER SH. NEERAJ SHARMA Petitioner
 Through: Mr. Ashok Agarwal, Mr. Kumar
 Utkarsh, and Mr. Manoj Kumar,
 Advocates.
 Ms. Shyel Trehan, Mr. Rohan Poddar

& Ms. Shivalika Rudrabatla, Adv.

versus

UNION OF INDIA & ANR.

..... Respondents

Through:

Mr. Sushil Raaja, SPC, UOI.

Mr. Kirtiman Singh, CGSC with Ms. Vidhi Jain, Adv. for UOI.

(90)

WITH

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W.P.(C) 4538/2023 & CM APPL.17337/2023

SANDEEP KALIA

..... Petitioner

Through:

Mr. Ashok Agarwal, Mr. Kumar Utkarsh, and Mr. Manoj Kumar, Advocates.

Ms. Shyel Trehan, Mr. Rohan Poddar & Ms. Shivalika Rudrabatla, Adv.

versus

UNION OF INDIA & ANR.

..... Respondents

Through:

Mr. Kirtiman Singh, CGSC with Ms. Vidhi Jain, Adv. for UOI.

Mr. Mukul Singh CGSC, Ms. Ira Singh, Adv. for R-1. (M: 9971359513)

(91)

WITH

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W.P.(C) 4539/2023 & CM APPL.17340/2023

RAJVEER SRIVASTAVA THROUGH HIS

NEXT FRIEND AND NATURAL FATHER

SH. RAJESH KUMAR RIVASTAVA

..... Petitioner

Through:

Mr. Ashok Agarwal, Mr. Kumar Utkarsh, and Mr. Manoj Kumar, Advocates.

Ms. Shyel Trehan, Mr. Rohan Poddar & Ms. Shivalika Rudrabatla, Adv.

versus

UNION OF INDIA & ORS.

..... Respondents

Through:

Mr. Kirtiman Singh, CGSC with Ms. Vidhi Jain, Adv. for UOI.

Mr. Mukul Singh CGSC, Ms. Ira Singh, Advocate for R-1.

(92)

WITH

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W.P.(C) 4591/2023 & CM APPL. 17548/2023

VANSH THROUGH HIS NEXT FRIEND AND NATURAL
FATHER SH. VIPIN KUMAR

..... Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh, and Mr. Manoj Kumar,
Advocates.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ORS.

..... Respondents

Through: Mr. Kirtiman Singh, CGSC with Ms.
Vidhi Jain, Adv. for UOI.
Ms Monika Arora (CGSC) , Mr Yash
Tyagi , Adv.
Mr. Mukul Singh CGSC, Ms. Ira
Singh, Advocate for R-1.

(93)

AND

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W.P.(C) 5102/2023 & CM APPL.19968/2023

PRANSHU NAMDAR THROUGH HIS NEXT FRIEND AND
NATURAL FATHER SH. PARIXIT NAMDHAR

..... Petitioner

Through: Mr. Ashok Agarwal, Mr. Kumar
Utkarsh, and Mr. Manoj Kumar,
Advocates.
Ms. Shyel Trehan, Mr. Rohan Poddar
& Ms. Shivalika Rudrabatla, Advs.

versus

UNION OF INDIA & ANR.

..... Respondents

Through: Ms. Ritu Reniwal (SPC UOI).
Ms. Perna Dhall, Advocate of UOI.
(M: (8920466128)

(94)

WITH

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W.P.(C) 5726/2023 & CM APPL. 22436/2023

MASTER HARENDER THROUGH HIS NEXT FRIEND AND
NATURAL FATHER SH. SUNDER SINGH & ANR.

..... Petitioners

Through: Mr. Ashok Agarwal, Mr.Kumar
Utkarsh & Mr. Manoj Kumar, Advs.
(M: 9811101923)

versus

UNION OF INDIA & ORS.

..... Respondents

Through: Mr Neeraj, SPC with Mr. Sahaj Garg & Mr Vedansh Anand, Advocates for UOI (M: 8076802450).
Mr. Tanveer Oberoi, Advocate for (AIIMS).

(95)

WITH

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W.P.(C) 5753/2023 & CM APPL. 22528/2023

VINAY THROUGH HIS NEXT FRIEND AND NATURAL

FATHER SH. MEHAR SINGH

..... Petitioner

Through: Mr. Ashok Agarwal, Mr.Kumar Utkarsh & Mr. Manoj Kumar, Advs. (M: 9811101923)

versus

UNION OF INDIA & ORS.

..... Respondents

Through: Mr Atul Krishna Senior Panel Counsel, Mr Hardik Bedi GP. (M: 8010414123)

(96)

AND

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W.P.(C) 6089/2023 and CM APPL. 23902/2023

MASTER SAIANSH THROUGH HIS NEXT FRIEND AND

NATURAL FATHER SH. AVTAR SINGH

MALHOTRA

..... Petitioner

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

versus

UNION OF INDIA & ANR.

..... Respondents

Through: Mr. Kirtiman Singh, CGSC with Ms. Vidhi Jain, Adv.

Mr Atul Krishna Senior Panel Counsel, Mr Hardik Bedi GP.

CORAM:**JUSTICE PRATHIBA M. SINGH****Prathiba M. Singh J. (Oral)**

1. This hearing has been done through hybrid mode.
2. The present batch of petitions has been filed by the Petitioners who are children suffering from rare diseases. The case of the Petitioners is that

medicines and therapies for the said diseases are exorbitantly expensive and if the same are not made available, the health and physical well-being of these children would be severely jeopardised. These matters have been heard by the Court from time to time and various directions have been issued for enabling treatment and making medicines available to the Petitioners.

Trials for Development of Indigenous Therapies

3. On 20th April, 2023, this Court was informed that ICMR is willing to fund the on-site trials of the therapies that are currently being developed by Hanugen-BIRAC. However, manufacturing of the drugs would have to be carried out by the company concerned, and the cost of manufacturing would also have to be borne by the company. On 3rd May, 2023, Id. Counsel for BIRAC submitted that Hanugen has informed BIRAC that it had arranged its share of funds in terms of the Grant-in-aid Letter Agreement (GLA), and that BIRAC is also willing to continue to honour the said agreement.

4. Today, Dr. Shastry from DART and Mr. Amit Kumar appearing for BIRAC submit that the second tranche of Rs.92 lakhs has been arranged by Hanugen and now, in terms of the GLA, contribution of BIRAC is to be made. It has further been brought to the attention of the Court that as per the affidavit dated 10th May, 2023, ICMR has agreed to provide full support, both technical and financial, to clinical trials at four trial sites. The relevant portion of the said affidavit reads as under:

“7. It is respectfully submitted that the present instance has provided an opportunity to encourage research & development of new drugs by way of augmenting and expediting clinical trials. In this connection, it is humbly submitted that the clinical trial protocol for conducting the regulatory clinical trial has specified the following 9 trial sites:

- i. Indira Gandhi Institute of Child Health, Bengaluru
- ii. Sir Ganga Ram Hospital, New Delhi;
- iii. All India Institute of Medical Sciences, New Delhi;
- iv. Postgraduate Institute of Medical Education & Research, Chandigarh;
- v. SMS Medical College, Jaipur;
- vi. All India Institute of Medical Science, Bhopal;
- vii. CIMS Hospital, Ahmedabad;
- viii. KEM Hospital, Pune &
- ix. Nizam's Institute of Medical Sciences, Hyderabad.

Out of these 9 sites, ICMR has agreed to full support (both technically and financially), the clinical trials at the following 4 trial sites:-

- I) AIIMS, New Delhi.
- II) PGIMER, Chandigarh
- III) Indira Gandhi Institute of Child Health, Bangalore
- IV) Sir Ganga Ram Hospital, New Delhi

8. It is respectfully submitted that Department of Health & Family Welfare is fully committed towards expeditious clinical trial of drugs, generation of clinical trial data, its submission to the national regulator i.e. Drug Controller General of India (DCGI), its consideration & approval by DCGI for treatment of Rare Diseases. In addition, Biotechnology Industry Research Assistance Council (BIRAC) under the Department of Bio- Technology (DBT) has already committed on record, before this Hon'ble Court to fund 50% of the funds required for research and trial of such drugs.

9. ICMR has committed for fully supporting on site trial, as multi-centric trial shall be essential for assessing the efficacy as well as contra indications of the drugs. Once clinical trial progresses and data are generated, Department of Health & Family Welfare as well as ICMR shall get the data analysed by a scientific

institution of repute for submission before DCGI. Hence, even the data analysis cost will be borne by the Government. This all will cover a major part of the proposed expenditure for the clinical trial of drugs. The promoter companies, since they would be selling the drug (once approved), as a commercial enterprise, would need to invest the balance of financial resources.”

5. In view of the above, let the clinical trials by M/s Hanugen proceed further. Since the funds have been now arranged by Hanugen, BIRAC shall without delay make its contribution of the second tranche. In order to streamline the manner in which the manufacturing of the doses and the on-site trials can take place, **let a meeting be held between Hanugen, BIRAC and representatives of ICMR in the week commencing 22nd May 2023.** In the meeting to be held, they shall chalk out the time table for the clinical trials in terms of the approved protocols.

6. Let an updated status report be filed by the next date of hearing by the Id. CGSC after obtaining instructions from BIRAC and ICMR.

Constitution of National Rare Diseases’ Committee

7. On the last date of hearing, it was brought to the attention of the Court that an email dated 10th May, 2023 had been received from M/s Sarepta. As per the said email, Sarepta is willing to discuss with the Government of India for making available the medications for DMD. The relevant portion of the order dated 10th May 2023 dealing with this aspect is extracted below:

“5.It is submitted on behalf of one of the Petitioners that as per an email sent on behalf of Sarepta, the said company is also willing to discuss a subscription model with the Government of India in which the Government can pay annual fees for blocks of patients. It has further

been stated in the email that by the end of the year, almost 80 patients of DMD will obtain free of cost medication as part of Sarepta's clinical trials."

8. In view of this development, the Court had directed the Id. CGSC to take instructions in this regard.

9. Today, Id. counsel for the parties, Ms. Trehan, Id. *Amicus* and Mr. Kirtiman Singh, Id. CGSC have been heard.

10. The Court has also been informed that the email from Sarepta which was placed on record by Id. Counsel for the Petitioners on the last date of hearing has been followed up by Sarepta by a second email dated 15th May, 2023 which has been handed over to the Court today. The said email reveals that there is a possibility of obtaining treatment for DMD patients if the Government contacts the company.

11. The Court has been hearing petitions relating to children suffering from rare diseases since early 2021. The Court has also been supervising administration of therapies to the Petitioners, formulation of an effective framework to treat rare diseases, and indigenisation of therapies amongst other activities.

12. The Ministry of Health & Family Welfare had framed the National Policy for Treatment of Rare Diseases, 2017 but due to challenges faced in its implementation, the 2017 Policy was put in abeyance till a new policy was framed. A Draft Health Policy for Rare Diseases was released in 2020, however, the Court was of the opinion that since human lives were at stake, the policy needs to be finalized in a time bound manner.

13. During the hearing of the present batch of petitions, the Court was informed that there are various organizations and companies in India which

are working on formulating therapies for DMD. In view of this position, a nine-member Committee was constituted by the Court vide order dated 2nd March, 2021 to submit a report on ways of providing treatment and therapies to children suffering from rare diseases, and the steps needed to be taken to indigenize the development of therapies in India.

14. Upon receiving the report of the Committee, and hearing submissions of the parties, the Court vide order dated 23rd March, 2021 passed the following directions:

“21. In view of the above, the following directions are issued by this Court:

*i) **The ‘National Policy for Rare Diseases’ shall be finalized and notified by the Government of India, on or before 31st March, 2021.***

ii) As a part of the said policy, the ‘National Consortium for Research and Development on therapeutics for Rare Diseases’ shall also be set up.

iii) A Rare Diseases Committee shall be set up at AIIMS consisting of Prof. (Dr.) Madhulika Kabra and Prof. (Dr.) P. Ramesh Menon, who shall examine the applications for treatment and funding, received from any patient suffering from Rare Diseases. The said Committee can, depending upon the condition of the patient, also co-opt any one member from any specialized field into the said Committee. The Committee would, upon examination, recommend the kind of treatment which would be made available to the patients. Upon the approval of the Committee, the expenses for the treatment involved shall be drawn from the Rare Diseases Fund after approval by the Director, AIIMS.

iv) The entire unspent budget allocated for Rare Diseases, for the years 2018-19, 2019-20 and 2020-21, as per the amounts extracted above, shall be immediately moved into a fund called the ‘Rare

Diseases Fund', which shall be managed and utilized by AIIMS, which shall serve as a nodal agency for this fund. A separate bank account for the Rare Diseases Fund shall be opened by the Director, AIIMS for this purpose.

v) *The digital platform that is created in the Policy, for the purposes of receiving crowdfunding and other kinds of funding, shall be linked to the Rare Diseases Fund.* All individuals, organizations, companies etc., who wish to contribute to the said fund, shall make direct contributions. The Rare Diseases Fund shall be under the direct control and supervision of the Director, AIIMS. Periodic reports may be called for, by the Ministry of Health and Family Welfare, UOI, from AIIMS, in respect of the contributions that are received, as well as qua the utilization of the said fund.

vi) *The other Institutes which shall be notified under the policy, as centres for excellence, for Rare Diseases shall also be entitled to receive applications from patients who need treatment, and shall forward the same to the Rare Diseases Committee based in AIIMS.*

vii) In the case of direct applications being made to AIIMS, a decision shall be taken by the Rare Diseases Committee within a period of two weeks, in respect of the treatment and funding etc. In case, the application is routed through other institutes/ centres of excellence which are notified in the Health Policy for Rare Diseases, a decision upon the treatment and funding shall be taken by the Committee within a period of four weeks.

viii) In the context of Rare Diseases, the Government may consider increasing the budget for the year 2021-22 for the Rare Diseases Fund.

ix) *The National Consortium for Research and Development on therapeutics for Rare Diseases shall be the nodal agency for supervising and monitoring the indigenization of treatments and therapies, manufacture of drugs, technology transfer, approvals,*

etc. for Rare Diseases. The said Consortium, as recommended in the report, shall consist of representatives from DBT, ICMR, DST, CSIR, DCGI, and other related Ministries and Departments. DBT and ICMR shall jointly take the lead.

x) *The Consortium shall also make recommendations, if any, as to whether the patients suffering from Rare Diseases ought to be included in any of the clinical trials currently taking place.*

xi) *The Consortium, while monitoring Research and Development, shall also approve applications for funding of research projects in respect of treatment and therapies for Rare Diseases. The Amounts from the 'Rare Diseases Fund' may be utilised for the purpose of Research. All projects approved shall have specific deliverables and timelines. The amounts shall be released for this purpose only after the project is approved by the Chairperson of the Consortium or an official, not below the level of Joint Secretary, Ministry of Health and Family Welfare, until the consortium is fully operational. Upon a project being approved by the Chairperson of the Consortium/Joint Secretary, the amount from the Rare Diseases Fund shall be released for the said project.*

xii) *The National Policy for Rare Diseases shall also deal with any limits/ caps that are to be imposed for various categories of Rare Diseases, only if required.*

xiii) **Any financial incentives to be given for manufacturing/ Research and Development of therapies for Rare Diseases shall also be explored in the Policy**

xiv) *The Policy shall also explore as to whether any financial incentives are to be given to the companies, who could contribute for the treatment/ Research and Development relating to Rare Diseases.*

22. The National Policy for Rare Diseases shall incorporate the above directions, prior to it being notified by the Union

of India.

15. On 19th April, 2021, the Court was informed that in compliance of order dated 23rd March, 2021, the National Policy for Rare Diseases, 2021 (*hereinafter 'Policy'*) was notified on 30th March, 2021. Some of the important portions of the Policy reads as under:

"2. Rare Diseases: Issues & Challenges

The field of rare diseases is complex and heterogeneous. The landscape of rare diseases is constantly changing, as there are new rare diseases and conditions being identified and reported regularly in medical literature. Apart from a few rare diseases, where significant progress has been made, the field is still at a nascent stage. For a long time, doctors, researchers and policy makers were unaware of rare diseases and until very recently there was no real research or public health policy concerning issues related to the field. This poses formidable challenges in development of a comprehensive policy on rare diseases. Nevertheless, it is important to take steps, in the short as well as long term, with the objective of tackling rare diseases in a holistic and comprehensive manner.

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7. Policy Direction

The policy aims at lowering the incidence and prevalence of rare diseases based on an integrated and comprehensive preventive strategy encompassing awareness generation, premarital, post-marital, pre-conception and post-conception screening and counselling programmes to prevent births of children with rare diseases, and within the constraints on resources and competing health care priorities, enable access to affordable health care to patients of rare diseases which are amenable to one-time treatment or relatively low cost therapy.

Considering the limited data available on rare diseases, and in the light of competing health priorities, the focus

would be on prevention of rare diseases as a priority for all the three groups of rare diseases identified by Experts. Public Health and hospitals being a State subject, the Central Government would encourage & support the States in their endeavour towards screening and prevention of rare diseases through Centres of Excellence under Rare Disease Policy and Nidan Kendras under Department of Biotechnology.

XXX XXX XXX

10. Government of India support in treatment

The following initiatives shall be taken for patients of Rare Diseases:

- i. Financial support upto Rs. 20 lakh under the Umbrella Scheme of Rashtriya Arogya 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.
- ii. State Governments can consider supporting patients of such rare diseases that can be managed with special diets or hormonal supplements or other relatively low cost interventions (Diseases listed under Group 2).
- iii. Keeping in view the resource constraints, and a compelling need to prioritize the available resources to get maximum health gains for the community/population, the Government will endeavour to create alternate funding mechanism through setting up a digital platform for voluntary individual and corporate donors to contribute to the treatment cost of patients of rare diseases.

13. Increasing affordability of drug related to rare diseases

(a) Research & Development activities on rare diseases

Indian Council of Medical Research (ICMR), Department of Biotechnology, Department of Pharmaceuticals, Department of Science and Technology and Council of Scientific & Industrial Research will be requested to promote research and development in the field of rare diseases for diagnosis and treatment of rare diseases.

Creation of an integrated research pipeline to start the development of new drugs, for which pharmaceutical companies would be encouraged and research organizations as well as funding agencies would be involved in this important endeavour. Research for repurposing the drugs and use of biosimilar would be encouraged. Approval for new drugs and decision related to trials will continue to be provided by Drugs Controller General of India under the New Drugs and Clinical Trial Rules, 2019.

(b) Ministry of Finance will be requested for reduction in custom duties on import of medicines related to rare diseases.

(c) Ministry of Chemicals and Fertilizers, Department of Pharmaceutical (DoP), National Pharmaceutical Pricing Authority (NPPA) shall take measures to document and make publicly available the prices of drugs for rare diseases and work towards affordability of drugs for rare diseases, in consultation with the Ministry of Health and Family Welfare.

(d) Measures for creating conducive environment for indigenous manufacturing of drugs for rare diseases would be taken. Department of Pharmaceuticals, Department for Promotion of Industry and Internal Trade (DPIIT) will be requested to promote local development and manufacture of drugs for rare diseases at affordable prices and take legal/legislative measures for creating conducive environment for indigenous manufacturing of drugs for rare diseases at affordable prices. PSUs would be encouraged for local manufacturing of drugs for rare diseases.

16. The above amount of Rs. 20 lakhs has since been increased to Rs. 50 lakhs and has also been released for most of the Petitioners for whom treatment has been given. As can be seen from a perusal of the above Policy, the Government is keen on finding solutions to deal with the problems relating to rare diseases. However, the Policy does acknowledge various issues and challenges that are there in the treatment of rare diseases. Lack of data, awareness, and unavailability of treatment are the foremost challenges in devising a framework for the treatment of patients suffering from rare diseases. Prohibitively high prices of drugs and therapies that are used in the treatment of rare diseases is yet another factor that hinders easy and timely access to medicines.

17. During the hearings before the Court, it is realised that there is a need for some urgent steps to be taken in close coordination between the medical community, the providers of therapies for rare diseases and the Governmental agencies. Under the current framework, the Centres for Excellence are not centrally coordinated, leading to lack of timely availability and adequate therapies for patients with rare diseases – who are mostly children.

18. In order to implement the Policy in an efficient manner and to ensure that the benefits of the Policy reach the ultimate patients of rare disease who are the beneficiaries of the Policy, it is deemed appropriate to constitute the **National Rare Diseases' Committee (hereinafter "Committee")**.

19. It is submitted by Mr. Kirtiman Singh, Id. CGSC that the Committee could consist of representatives from the Ministry of Health and Family Welfare, ICMR, DCGI and some domain experts. There are various other suggestions also which have been made by Id. Counsels appearing for the Petitioners in respect of the persons and entities who ought to be included in

the Committee.

20. After hearing learned counsel for the parties, in order to ensure that the Committee can work in a streamline and an efficient manner, the National Rare Diseases' Committee is constituted with the following Members:

S.No.	Name of the Member	Capacity
1	Dr. Nikhil Tandon, Professor - AIIMS	Member
2	Secretary - Ministry of Health & Family Welfare or one of his nominee	Member
3	Director General - Indian Council for Medical Research	Member
4	Drug Controller General of India	Member
5	Dr. Madhulika Kabra, Professor - AIIMS	Member

21. The mandate of the Committee would broadly be to take all steps needed for implementation of the National Rare Disease Policy, 2021. The mandate of the Committee shall include:

- (i) Procurement of therapies & drugs and creation of associated logistical framework for administration of treatment for patients with rare diseases;
- (ii) Recommending necessary steps for the indigenisation of therapies, medicines for rare diseases and identify the manner in which the same can be made accessible to the lakhs of patients who, as per the Policy, are suffering from rare diseases;
- (iii) The Committee, while working broadly under the umbrella of the Policy, would undertake a periodic review of the Policy and recommend to the Ministry of Health and Family Welfare, the changes needed in the Policy if the same is deemed necessary.

22. In addition to the above mandate, the immediate requirement of the patients whose treatment has been stopped due to lack of funding, and whose

details have been captured in **paragraph 16** of the order dated 3rd May, 2023 shall be taken up by the Committee on an urgent basis, so that the treatment can be re-commenced. The Committee would be free to contact the providers or manufacturers or distributors of the DMD therapies as also other therapies, in a manner to ensure immediate commencement of providing adequate doses for the said patients.

23. The Committee is also free to consult any other persons or organisations as Invitees to the Committee meetings to work for the overall objective of the Policy. The Committee may also contact any subject expert or persons with domain knowledge for the sake of expediting the procurement of medicines or therapies. For the said purpose, if any contact details of the patients or the providers of therapies are required, Id. Counsel for the Petitioners, AIIMS or the Id. standing counsel is free to provide the same to the Committee.

Treatment of Patients at AIIMS

24. Insofar as AIIMS is concerned, Mr. Oberoi, Id. Counsel has handed over to the Court a chart in terms of the order dated 10th May, 2023, which shows that the number of patients who are enrolled with AIIMS, New Delhi suffering from DMD, SMA and other rare diseases are as under:

S. No.	Disorder/Rare Disease	No. of Patients Enrolled	No. of Patients Amenable to treatment
1	DMD	517	312
2	SMA	189	189
3	Other Rare Diseases (e.g.	166	116

	Lysosomal Storage Disorders. Gaucher, MPS, etc.)		
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25. The Committee shall also look into the case of these patients who have been enrolled and the manner in which their treatment can be commenced.

26. Insofar as the Petitioner in *W.P.(C) 5395/2021*- Master Ayushman Chaturvedi is concerned, Mr. Oberoi, Id. Counsel submits that the one vial left to be administered to Master Ayushman Chaturvedi was a wrong medicine which had been sent by the supplier. The same would be replaced by the distributor only in the next procurement cycle. This fact shall also be brought to the notice of the Committee.

27. The first meeting of the Committee shall be held between 17th May, 2023 and 21st May, 2023. A compilation of all the orders passed by the Court in these matters shall be placed before the Committee by the Joint Secretary, Mr. Rajiv Manjhi, Ministry of Health & Family Welfare. Until an Officiating Secretary is appointed, Mr. Manjhi shall coordinate with all the Committee members and act as the Officiating Secretary. The Committee is free to appoint or nominate any other Officiating Secretary, as may be deemed appropriate.

28. List before the Court on 29th May, 2023 at 2:30 pm.

PRATHIBA M. SINGH
JUDGE

MAY 15, 2023
DK/SK