

\$~15 to 37

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

+ W.P.(C) 9684/2021

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

..... Petitioner

Through

versus

UNION OF INDIA & ORS. Respondents

Through Mr Farman Ali and Mr.Athar Raza
Farooquei, Advs. for Union of India.
Mr. Saumya Tandon, Adv. for the R2/GNCTD

(16)

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

MASTER ARNESH SHAW Petitioner

Through Mr.Rahul Malhotra, Adv.

versus

UNION OF INDIA & ANR. Respondent

Through Mr. Chetan Sharma, ASG for UOI in
all matters from 14 to 35.
Mr. Tanveer Oberoi, Adv. for AIIMS in item nos.
14 to 35

(17)

+ W.P.(C) 10782/2020 & CM APPL. 33828/2020

AVIRAJ GARG, AGE 4 YEARS, THROUGH HIS NEXT FRIEND
AND NATURAL FATHER SH. ABHINAV GARG

..... Petitioner

Through Mr. Ashok Agarwal with Kumar Utkarsh Advocates for petitioners in item nos. 15, 16, 19, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33 & 34

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. Chetan Sharma, ASG with Mr. Ripudaman Bhardwaj, CGSC with Sahaj Garg, Vinay Yadav, Akshay Gadeock, Amit Gupta, Kushagra Kumar Advs. and Mr. Manish Raj U/s MoHFW for Respondent No. 1-UOI
Ms. Amrita Prakash, Central Government Standing Counsel for respondent no.1 (UoI)

(18)

+ W.P.(C) 322/2021 & CM APPL. 812/2021
KESHAV SHARMA AGE 12 YEARS THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SANJEEV KUMAR

..... Petitioner

Through

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr Chetan Sharma ASG with Mr. Shankar Kumar Jha, SPC with Mr. Amit Gupta, Mr. Vinay Yadav, Mr. Akshay Gadeock and Mr. Sahaj Garg, for UOI.

(19)

+ W.P.(C) 1491/2021 & CM APPL. 4291/2021
MASTER MEDHANSH JHAWAR @ MADHAV

..... Petitioner

Through

versus

UNION OF INDIA & ANR.

..... Respondent

Through

(20)

+ W.P.(C) 1511/2021, CM APPL. 4331/2021 & CM APPL. 4332/2021
MASTER KENIT JHAWAR @ KESHAV

..... Petitioner

Through

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. Prakash Kumar, Central Govt Sr.
Counsel for Respondent No. 1/UOI.

(21)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr Chetan Sharma ASG with Mr.

Shankar Kumar Jha, SPC with Mr. Amit Gupta,
Mr. Vinay Yadav, Mr. Akshay Gadeock and Mr.
Sahaj Garg, for UOI.

(22)

+ W.P.(C) 3662/2021

PAYEL BHATTACHARYA

..... Petitioner

Through Mr. Aditya Chatterjee, Ms. Nitya
Kaligotla, Ms. Pracheta Kar; Mr. Sumer Dev Seth,
Mr. Abhirup Ghosh, Advocates.
Mr. Anuj Aggarwal, ASC, GNCTD with Ayushi
Bansal, Adv.
For respondent no.2 - GNCTD

versus

UNION OF INDIA & ORS.

..... Respondent

Through Mr. Chetan Sharma, ASG with Ms.
Anju Gupta advocate for respondent UOI R 1.
Mr. Anuj Aggarwal, ASC, GNCTD with Ayushi
Bansal, Adv. for respondent no. 2

(23)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. Shankar Kumar Jha Sr. Panel

Counsel, UOI for Respondent no.01

(24)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr.Sanjeev Uniyal with Mr. Dhawal
Uniyal, Advs. for UOI.

Mr. Anuj Aggarwal, ASC, GNCTD with Ayushi
Bansal, Adv.

For respondent no.2 - GNCTD

(25)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through

(26)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. Siddharth Khatana, Adv. (Senior
Panel Counsel) For Respondent no.1/UOI

(27)

+ 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.

..... Petitioner

Through

versus

UNION OF INDIA & ANR.

..... Respondent

Through

(28)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. Ranvir singh (CGSC)
For Respondent No.1

(29)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. N.K.srivastava senior panel
counsel for respondent no1

(30)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. Harish Kumar Garg, Payal
Agrawal and Saksham Garg, Advs for Respondent

no. 1

(31)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. Sanjeev Sabharwal SeniorPanel
Counsel for UOI for respondent UOI

(32)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through

(33)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. Satya Ranjan Swain, (Central Government Senior Panel Counsel) with Mr. Kautilya Birat for Respondent No. 1- (Ministry of Health and Family Welfare-UIO)

(34)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. Sanjeev Sabharwal, Sr. Counsel for UON/R-1.

(35)

+ 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

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. Ranvir singh (CGSC)
For Respondent No.1

(36)

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

..... Petitioner

Through

versus

UNION OF INDIA & ANR.

..... Respondent

Through Mr. Awadhesh Kr. Singh, for R-1.

(37)

+ W.P.(C) 5395/2021 & CM APPL. 16686/2021 (interim direction)
MASTER AYUSHMAN CHATURVEDI

..... Petitioner

Through Mr. Gautam Barnwal, Adv. for Mr.
Anurag Ojha, Adv. for petitioner

versus

UNION OF INDIA & ORS.

..... Respondent

Through Mr. Neeraj Kumar, Sr. Central Govt.
Counsel for R-1. /Applicant
Mr. Mr. G.D.Sharma Adv for R - 4

CORAM:
HON'BLE MS. JUSTICE REKHA PALLI

ORDER
20.09.2021

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1. In the present batch of petitions, where the Court is dealing with the problems being faced by persons, most of whom are children suffering from rare diseases, extensive directions were passed on 23.03.2021 to ensure that these patients are able to receive the medical treatment necessary. It appears that even after a period of six months some of the directions issued by this Court are yet to be complied with by the respondents/Union of India.
2. One such direction was for transfer of the entire unspent budget allocated for 'Rare Diseases' for the years 2018-19, 2019-20 and 2021-21 to the Rare Diseases Fund, which unspent amount, the Court observed was about Rs.193 crores.
3. Today, it is an admitted position that although in accordance with the directions of this Court, a bank account has been opened for transfer of this amount, only a small fraction of the unspent amount has been transferred to the said account. No explanation is forthcoming for not transferring the balance amount.
4. On the last date, this Court after noticing the fact that though the Union of India had created a crowd funding platform by the name of <http://rarediseases.nhp.gov.in/>, the names of the petitioners were not uploaded thereon, had directed the respondents to ensure that their names are duly uploaded on the abovementioned portal.
5. The learned ASG submits that the petitioners' names could not be

uploaded on the said portal as they are first required to be examined by doctors at one of the eight centres of excellence being run by the Union of India, for which purpose they may contact the nodal officers at any of these centres, details whereof are below:

S. No.	Name of Centers of Excellence	Name of Nodal Officer/Email id/Contact No.
1	All India Institute of Medical Sciences, New Delhi	Dr. Neerja Gupta, Associate Professor Division of Genetics. Department of Pediatrics, AIIMS, New Delhi, neerjal7@gmail.com. 9868397529
2	Maulana Azad Medical College, New Delhi	Dr. Meenakshi Bothra, Assistant Professor, Division of Genetics, Department of Pediatrics. MAMC, New Delhi Email: meenakshibothra@gmail.com 8700509704
3	Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow	Dr. Shubha Phadke, M D Professor & Head. Department of Medical Genetics, Sanjay Gandhi Lucknow.India-226014 Postgraduate Institute of Medical Sciences, Phone: 9839220199, 91522-2494325 E-mail: shubharaophadkeu.gmail.com

4	Post Graduate Institute of Medical Education and Research, Chandigarh	Dr. Ranjit Pal Singh Bhogal, Assistant Professor, Deputy Medical Superintendent. Department of Hospital Administration. Contact No. 7087002089 majorbhogal1984@gmail.com
5	Centre for DNA Fingerprinting & Diagnostics with Nizam's Head. Diagnostics Division Institute of Medical Sciences. ashwindalal@gmail.com Hyderabad	1. Dr. Ashwin Dalal, Centre for DNA Fingerprinting & Diagnostics with Nizam's Head. Diagnostics Division Institute of Medical Sciences. ashwindalal@gmail.com Hyderabad Contact No. 040-27216147
6	King Edward Medical Hospital, Mumbai	Dr. Akash Shukla. Mobile No 9869256376 Email id: drakashshukla@yahoo.com
7	Institute of Post-Graduate Medical Education and Research, Kolkata	Prof. Suchanda Mukherjee, HOD. Neonatology 9831485596 drsmukherjee70@gmail.com
8	Center for Human Genetics (CHG) with Indira Gandhi Hospital, Bengaluru	Dr. Sanjeeva GN. Associate Professor, Indira Gandhi Institute of Child Health. Bengaluru Mob: 9945657034 Email: sanju.en26@gmail.com

6. On the other hand, learned counsel for the petitioners submit that even

though all the petitioners had already submitted applications to the aforesaid centres of excellence, they have till date not received any information in this regard.

7. Be that as it may, the petitioners/their Authorized Representatives are directed to contact the Nodal Officers whose mobile numbers have been noted hereinabove within two days from today, who will then facilitate the process of examination of the relevant reports of the petitioners so that their details can be uploaded on the portal within 10 days from today.
8. It further transpires that on 11.08.2021 this Court, in the light of the petitioner's plea in W.P.(C) 3662/2021 and upon a perusal of the order passed by the Kerala High Court in W.P.(C) 7894/2021 clearly showing that funds to the tune of Rs.63 crores collected from the general public for the treatment of a person suffering from a Rare Disease, who unfortunately expired, were lying unutilized, had therefore directed that steps be taken by the Union of India to ensure that the said funds are utilized for treatment of the present petitioners and other similarly placed patients under the National Policy for Rare Diseases, 2021.
9. In purported compliance of the said order, the Union of India has filed an affidavit, stating therein that as it is not a party to the said petition, it has not been able to take steps for the transfer of the said amount to the Rare Diseases Fund. This stand is wholly unacceptable. On the contrary, learned counsel for the petitioner points out that the Union of India has in fact been arrayed as respondent no. 5 in the petition pending before the Kerala High Court. In my considered opinion,

even if the Union of India were not a party to the said petition, it was expected that it would take expeditious steps to ensure that the said amount does not lie unutilized and is forthwith transferred to the Rare Diseases Fund.

10. At this stage, learned ASG assures the Court that an appropriate application will be moved before the Kerala High Court within one week from today. He therefore seeks a short accommodation. While adjourning the matter at request of the learned ASG, it is directed that a comprehensive compliance affidavit be filed by the UOI as also by AIIMS within three weeks clearly setting out as to how they have complied with the directions issued by this Court on 23.03.2021 and on subsequent dates.

11. List the petitions on 27.10.2021.

REKHA PALLI, J

SEPTEMBER 20, 2021

acm/ss