

IN THE HIGH COURT OF KARNATAKA, BENGALURU

DATED THE 30TH DAY OF SEPTEMBER 2021

BEFORE

BY HON'BLE MR. JUSTICE KRISHNA S DIXIT

WRIT PETITION NO 17626/2021 (GM-RES)

PETITIONER

MASTER. JANISH N
AGED ABOUT 1 1/2 YEARS
S/O NAVEEN KUMAR N
SINCE MINOR REPRESENTED BY HIS FATHER
NAVEEN KUMAR N S/O NARASIMHAIAH
NO. 1910, 8TH CROSS, 3RD MAIN, WATER TANK ROD,
NEAR WATER TANK, SANJEEVINI NAGAR, BANGALORE 560092



BY SRI/SMT PRINCE ISAC, BHAVYA A C & GIRISHA T R
VS

RESPONDENTS

- 1 UNION OF INDIA
REP BY ITS SECRETARY
MINISTRY OF HEALTH AND FAMILY WELFARE
ROOM NO. 348 A WING, NIRMAN BHAVAN, NEW DELHI 110011
- 2 SECTION OFFICER (FUNDS)
PRIME MINISTER'S
NATIONAL RELIEF FUND (PMNRF)
PRIME MINISTER'S OFFICE, SOUTH BLOCK, NEW DELHI 110011
- 3 THE STATE OF KARNATAKA
REP BY ITS CHIEF SECRETARY
VIDHANA SOUDHA, BANGALORE 560001
- 4 THE SPECIAL OFFICER
NO. 235/A, 2ND FLOOR, CMRF SECTION
VIDHANA SOUDHA, BANGALORE 560001
- 5 PRINCIPAL SECRETARY TO THE
GOVERNMENT OF KARNATAKA
DEPARTMENT OF HEALTH AND FAMILY WELFARE
NO.105, 1ST FLOOR, VIKAS SOUDHA, BANGALORE 560001

(VCO DTD 27/09/2021, SRI M N KUMAR, CGC FOR R1 & R2;
SRI SRIDHAR HEGDE, HCGP FOR R3 TO R5)

Whereas, a Writ Petition filed by the above named petitioner under Article 226 & 227 of the Constitution of India, has been registered by this court.

-: 2 :-

After hearing, the Court made the following:-

ORDER

XEROX COPY OF THE ENTIRE ORDER DATED 30/09/2021 IS ENCLOSED
HEREWITH SEPARATELY.

Contd../-

Um-01102021.9



KSDJ:
30.09.2021

W.P.No.17626/2021

ORDER

Learned Senior CGC has filed a Memo dated 01.10.2021 on behalf of respondent Nos.1 & 2 along with the National Policy for Rare Diseases, 2021 at Annexure-R1 wherein paragraph 7 reads as under:

"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 counseling 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."

Banking upon the said paragraph, learned CGC submits that the infant can be taken to Indira Gandhi Institute of Child Health, Bengaluru, situated in the

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Compound of NIMHANS forthwith, and that one Dr.G.N.Sanjeev, Associate Professor shall prima facie examine the infant and refer it to the Expert Committee who shall adhere to the paragraph Nos. 16 & 17 of the Memo; Learned CGC banks upon paragraphs 16 & 17 in support of the said version.

In view of the above, the infant shall be taken to NIMHANS Compound for being examined by aforesaid Dr. Sanjeev today itself.

Petitioner guardians are permitted to contact the said Doctor either through E-mail or mobile phone or otherwise; if the petitioner's guardians calls or message, the said Doctor shall respond to the same immediately and that non-responding shall be viewed very seriously.

If something happens to the Child because of arguable culpability qua the respondents concerned of the doctors, they shall be made personally liable.

Call this matter on 07.10.2021 for updating the process/progress in the matter.



604
07/10/21

Copy
2/10/21
Assistant Registrar
High Court of Karnataka
Bangalore - 560 001
2/10/21