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

Date of decision: 23rd March, 2020

+ **W.P.(C) 2943/2020**

ALISHBA KHAN

..... Petitioner

Through: Mr. Rahul Malhotra & Mr. Manas
Tripathi, Advocates (M-9899218215)

Versus

UNION OF INDIA AND ORS.

..... Respondents

Through: Mr. Anuj Aggarwal, ASC, GNCTD
(M-989136318)

CORAM:

JUSTICE PRATHIBA M. SINGH

Prathiba M. Singh, J. (Oral)

CM APPL. 10228/2020

1. This is an application for exemption from filing typed translated copies of certain annexures. Exemption allowed, subject to all just exceptions.
2. Application is disposed of.

W.P.(C) 2943/2020 & CM APPL. 10227/2020

3. The Petitioner is an 18 month old girl suffering from a rare disease called 'Gaucher'. She, through her father, has filed the present petition seeking funds for her treatment as well as directions for treatment to be given to her as repeated representations to various governmental authorities have not been fruitful.
4. Though the Government of India had come out with a National Policy

for Treatment of Rare Diseases, in 2018, due to objections by certain state governments, the same was reportedly scrapped and a draft policy document for rare diseases was released on 13th January, 2020. However, the same has not yet come into effect. Owing to this, there appears to be no policy in place at this point for dealing with persons with rare diseases and how treatment is to be provided to them. It is pleaded that 'Gaucher' has been treated as an 'orphan disease' in the U.S. and in the European Union.

5. On a query, Ld. Counsel for the Petitioner submits that the monthly cost of treatment is approx. Rs. 3.5 lakhs. The expense for this treatment is quite steep which the Petitioner's family cannot afford. Considering the age of the child and given that the policy for rare diseases is yet to be finalised by the Government, it is deemed appropriate to direct Respondent No.3 – AIIMS to start the treatment of the Petitioner without charging anything from the Petitioner. Further directions in respect of the expenses towards the said treatment would be passed after the Union of India enters appearance in the matter.

6. Copy of this order be communicated to the Medical Superintendent, AIIMS as well as the Director, AIIMS, with the request to commence the treatment of the Petitioner immediately. The Registry to communicate this order directly to the Medical Superintendent, AIIMS and the Director, AIIMS. Let the Standing Counsel for AIIMS be also sent a copy of this order. Copy of this petition be also served upon Mr. Amit Mahajan, Id. Standing Counsel for the Union of India along with a copy of this order for the same to be communicated to the Ministry of Health and Family Welfare.

7. Union of India is directed to file an affidavit before the next date as to the current policy of the Government on rare diseases.

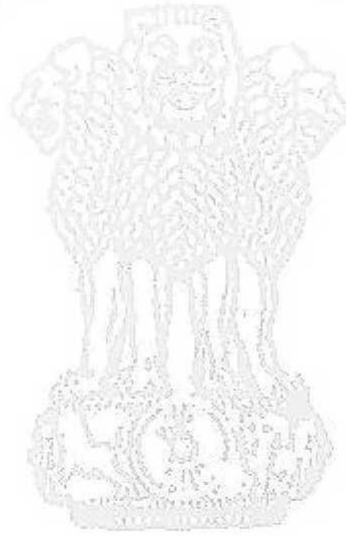
8. List on 17th April, 2020.
9. Copy of this order be given *dasti* under signature of the Court Master.

PRATHIBA M. SINGH
JUDGE

MARCH 23, 2020

Rahul/C

HIGH COURT OF DELHI



सत्यमेव जयते