**IN THE HIGH COURT OF KERALA AT ERNAKULAM**

**PRESENT**

**THE HONOURABLE THE CHIEF JUSTICE MR.S.MANIKUMAR**

**&**

**THE HONOURABLE MR. JUSTICE SHAJI P.CHALY**

**Wednesday, the 26th day of October 2022 / 4th Karthika, 1944**

**WP(C) NO. 30529 OF 2022(S)**

**SUO MOTU PUBLIC INTEREST LITIGATION INITIATED BY THE HIGH COURT TO INCLUDE CONGENITAL ADRENAL HYPERPLASIA IN THE GROUP OF RARE DISEASES AND TO GRANT FINANCIAL AID AND SUPPORT TO THE PATIENTS.**

**RESPONDENTS:**

**1.STATE OF KERALA, REPRESENTED BY THE CHIEF SECRETARY, GOVERNMENT OF KERALA,GOVERNMENT SECRETARIAT, THIRUVANANTHAPURAM-695001**

**2.THE PRINCIPAL SECRETARY TO GOVERNMENT,HEALTH AND FAMILY WELFARE DEPARTMENT,ROOM:301,GOVERNMENT SECRETARIAT ANNEXE-I THIRUVANANTHAPURAM-695001.**

**ADDL. R3 IMPLEADED**

**3.THE SECRETARY TO THE GOVERNMENT, MINISTRY OF HEALTH AND FAMILY WELFARE, GOVERNMENT OF INDIA, NEW DELHI.**

**ADDL. R3 IS IMPLEADED AS PER ORDER DATED 26/10/2022 IN WPC**

**This Suo motu Writ petition again coming on for admission upon perusing the petition and this Court's order dated 19/10/2022 and upon hearing the arguments of SRI.N.MANOJ KUMAR, STATE ATTORNEY for the respondents and of SRI.JAISHANKAR V.NAIR, CENTRAL GOVERNMENT COUNSEL and of SRI. K. R RANJITH, GOVERNMENT PLEADER, the court passed the following:**

**P.T.O.**

**S.MANIKUMAR, C.J. & SHAJI P. CHALY, J.**

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**W.P.(C)No.30529 of 2022 - S**

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**Dated this the 26th day of October, 2022**

**ORDER**

**S.MANIKUMAR, C.J.**

Under Secretary to the Government, Health and Family Welfare Department, Government Secretariat, Thiruvananthapuram has filed a counter affidavit on behalf of respondents 1 and 2 viz. State of Kerala, the Principal Secretary to the Government respectively, setting out the treatment given and expenses incurred, along with the supporting documents.

2. Based on Ext.P3 letter written by Smt.Smitha Antony, Vayalil (H), Kozhuvanal, Kottayam, Kerala to this court, seeking to include Congenital Adrenal Hyperplasia, as a rare disease, to grant financial aid and support to the patients, this suo motu writ petition has been initiated.



3. Inviting the attention of this court to Ext.P4 letter dated 21.7.2022 of the Ministry of Health and Family Welfare (Rare Diseases Cell), Government of India, addressed to Smt.Smitha Antony, Vayalil (H), Kozhuvanal, Kottayam, Kerala, Mr.K.R.Ranjith, learned Government Pleader submitted that the applicant had doubts regarding the bonafides and genuineness of the above said communication dated 21.7.2022.

4. On receipt of instructions from the Rare Diseases Cell, Ministry of Health and Family Welfare, Government of India, Mr.Jaishankar V. Nair, learned Central Government Counsel submitted that, in response to the representation of Smt.Smitha Antony, reply dated 21.7.22 has been given to

the effect that Central Technical Committee for Rare Diseases (CTCRD), Directorate General of Health Services, has examined the case and opined that Congenital Adrenal Hyperplasia (CAH) disease can be categorized as a Rare Disease under Group 2, for which, support can be provided by the State Government.

5. For brevity, abovesaid letter dated 21.7.22 is reproduced:

No.W-11037/65/2021-Grants (RD) (Part I)
Government India
Ministry of Health and Family Welfare
(Rare Diseases Cell)

Nirman Bhawan, New Delhi
Dated:21/07/2022

To

Smt.Smitha Antony,
Vayalil (H), Kozhuvanal P O
Kottayam, Kerala 686 573

Subject: Representation regarding inclusionof Congenital Adrenal Hyperplasia (CAH) disease in the rare disease list of National Policy for Rare Diseases (NPRD), 2021 – reg.

I am directed to refer to your representation dated 25.2.2022 on the subject mentioned above and to say that the matter was considered by Central Technical Committee for Rare Diseases (CTCRD), Directorate General of Health Services. The Committee examined the case and opined that Congenital Adrenal Hyperplasia (CAH) disease can be categorized as a Rare Disease under Group 2 for which support can be provided by the State Government and the treatment can be availed at any local tertiary hospital. Further action is being taken to include CAH into Group 2 of the Rare Disease under NPRD, 2021.

2. It is also informed that as per NPRD, 2021, 08 (Eight) Centres of Excellence (CoEs) have been identified, which are premier Government tertiary hospitals with facilities for diagnosis, prevention and treatment of rare diseases. The contact details of these 08 CoEs are enclosed at Annexure – I. In order to receive financial assistance for treatment of rare disease, the patient of the nearby area may approach the nearest Centre of Excellence to get him/her assessed and registered on the digital portal.

Yours faithfully,

Encl: As above

6. Though the Committee has opined that the abovesaid disease can be categorized as a rare disease, under Group 2, as per the National Policy

for Rare Diseases, 2021, a notification has to be issued by the Central Government.

7. In order to ascertain the further steps taken by the Ministry of Health and Family Welfare, as regards issuance of notification based on the opinion of the Central Technical Committee for Rare Diseases (CTCRD), we deem it fit that the Secretary to the Government, Ministry of Health and Family Welfare, Government of India, New Delhi should be impleaded as a party respondent in the writ petition, as he is a necessary and proper party for the prayer to be granted i.e., "to include Congenital Adrenal Hyperplasia in the group of rare diseases to grant financial aid and support to the patients".

8. Therefore, in exercise of powers conferred under Article 226 of the Constitution of India, the Secretary to the Government, Ministry of Health and Family Welfare, Government of India, New Delhi is arrayed as additional respondent No.3 in the writ petition. Registry is directed to make necessary changes wherever required.

Post on 3.11.2022.

**sd/-**
**S.MANIKUMAR**
**CHIEF JUSTICE**

**sd/-**
**SHAJI P. CHALY**
**JUDGE**

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**APPENDIX OF WP(C) 30529/2022**

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| **Exhibit P3** | **PETITION RECEIVED FROM SMT.SMITHA ANTONY AND ITS ENGLISH TRANSLATION.** |
| **Exhibit P4** | **LETTER FROM MINISTRY OF HEALTH & FAMILY WELFARE, GOVERNMENT OF INDIA DATED 21/07/2022.** |