# IN THE HIGH COURT OF KERALA AT ERNAKULAM Present:

THE HONOURABLE THE CHIEF JUSTICE MR.S.MANIKUMAR

THE HONOURABLE MR. JUSTICE SHAJI P.CHALY

Tuesday, the 27th day of October 2020/5th Karthika, 1942 <u>WP(C) No.28250/2017(S)</u>

#### **PETITIONER**

LYSOSOMAL STORAGE DISORDERS SUPPORT SOCIETY HAVING ITS OFFICE AT TOP FLOOR DUGGAL COMPLEX, SCHOOL ROAD, KHAN PUR, NEW DELHI-110062, REPRESENTED BY ITS STATE CO-ORDINATOR, KERALA CHAPTER, (SUDHEER BABU K.S, RESIDING AT KARUMKKIL HOUSE, KUNDANNOOR P.O, THRISSUR DISTRICT-680 590).

### **RESPONDENTS**

- STATE OF KERALA, REPRESENTED BY ITS CHIEF SECRETARY, GOVERNMENT SECRETARIAT, THIRUVANANTHAPURAM-695 001.
- 2. THE PRINCIPAL SECRETARY, HEALTH AND FAMILY WELFARE DEPARTMENT, GOVERNMENT SECRETARIAT, THIRUVANANTHAPURAM-695 001.
- 3. THE KERALA SOCIAL SECURITY MISSION,
  REPRESENTED BY ITS EXECUTIVE DIRECTOR, POOJAPPURA,
  THIRUVANANTHAPURAM-695 012.
- 4. THE KERALA MEDICAL SERVICES CORPORATION LTD,
  REPRESENTED BY ITS MANAGING DIRECTOR,
  NEAR WOMEN AND CHILDREN HOSPITAL, HEALTH AND WELFARE FAMILY COMPOUND,
  THYCAUD, THIRUVANANTHAPURAM, KERALA 695 014.
- 5. UNION OF INDIA, REPRESENTED BY ITS SECRETARY,
  HEALTH AND FAMILY WELFARE DEPARTMENT, CABINET SECRETARIAT,
  RAISINA HILL, NEW DELHI-110 011.

ADDL. R6 IMPLEADED

ADDL.R6. SANOFI GENZYME, REPRESENTED BY ITS GENERAL MANAGER (SOUTH ASIA) & HEAD- INDIA, SANOFI HOUSE, CTS NO.117-B, L&T BUSINESS PARK, SAKI VIHAR ROAD, POWAI, MUMBAI-400 072.

ADDL. R6 IS IMPLEADED AS PER ORDER DATED 01/08/2019 IN IA.3/2019 IN WPC.

Writ Petition (civil) praying inter alia that in the circumstances stated in the affidavit filed along with the WP(C) the High Court be pleased to direct the respondents to provide Enzyme Replacement Therapy, free of cost, to the children included in Ext-P2 list, pending disposal of the Writ Petition(Civil).

This petition again coming on for orders upon perusing the petition and the affidavit filed in support of WP(C) and this Court order dated 05/10/2020 upon hearing the arguments of M/S ADITHYA RAJEEV, ARJUN RAGHAVAN, JAIBY PAUL, T.R.HARIKUMAR, Advocates for the petitioner, GOVERNMENT PLEADER for R1 & R2, SRI.RANJITH THAMPAN, ADDL. ADVOCATE GENERAL FOR R1 TO R3, SRI.M. AJAY, STANDING COUNSEL for R4, SRI.RAJAGOPALAN. A., CENTRAL GOVERNMENT COUNSEL for R5, SRI.SUNIL SANKER & SRI.K.N.SIVASANKARAN, Advocate for Addl. R6, SRI.E.K. NANDAKUMAR, SENIOR ADVOCATE ALONG WITH SRI.M.GOPIKRISHNAN NAMBIAR, Advocate FOR OIL COMPANIES/PUBLIC SECTOR UNDERTAKINGS, SRI.NISAR AHAMMED K.T., MEMBER SECRETARY, KELSA, SRI.R.LAKSHMI NARAYAN, PRESIDENT, KERALA HIGH COURT ADVOCATES' ASSOCIATION, SRI.D. AJITHKUMAR, Advocate for KELSA and of SRI.M.R. SABU, SENIOR GOVERNMENT PLEADER, the court passed the following:

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

## W.A.No.2151 of 2017 & W.P.(C)No.28250 of 2017

Dated this the 27th day of October, 2020

### **ORDER**

### S.MANIKUMAR, C.J.

Order passed by this court on 5th October, 2020 reads as under:

"The Government is directed to ensure that the sum of Rs.50 lakhs exclusively earmarked for the purpose of treatment of the children affected with rare diseases, be deposited in the special account created for the purpose.

Mr.D.Ajithkumar, learned counsel appearing for the KeLSA submitted that steps are being taken to mobilise more funds through programmes, advertisement, etc.

Mr.M.Gopikrishnan Nambiar, learned Senior Counsel representing Oil Companies submitted that the discussion is being held for taking appropriate decision for providing funds for treatment of the children affected with rare diseases.

Post after two weeks."

2. By the abovesaid order, this court directed the Government to deposit the sum of Rs.50 lakhs in the special account created for the treatment of the children affected with rare diseases. In our earlier orders, we have observed the need to mobilise sufficient funds for providing continuous treatment to the children affected with rare diseases.

- 3. We have directed the KeLSA to generate more funds through programmes, advertisements, etc. and also directed Oil Companies to take appropriate decision for providing necessary funds for treatment of the children affected with rare diseases. But today, when this case came up for consideration, Mr.D.Ajithkumar, learned counsel appearing for the KeLSA submitted that despite the directions of this court, a sum of Rs.50 lakhs has not been deposited by the government in the special account created for the treatment of the children affected with rare diseases.
- 4. Orders of this court have to be respected and obeyed, if not appealed. In the above circumstances, we direct the Principal Secretary, Health and Family Welfare Department, Government Secretariat, Thiruvananthapuram (second respondent in W.P.(C)No.28250 of 2017) to appear in person, before this court on the next posting date and explain the reasons, for the non compliance of the directions of this court passed on 5th October, 2020 and also explain as to why the provisions of the Contempt of Courts Act, 1971 should not be invoked for non compliance of the directions of this court.

Post on 9.11.2020.

Sd/- S.MANIKUMAR, CHIEF JUSTICE Sd/- SHAJI P.CHALY, JUDGE

/true copy/

ASSISTANT REGISTRAR

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