

IN THE HIGH COURT OF KERALA AT ERNAKULAM

Present:

THE HONOURABLE THE CHIEF JUSTICE MR.S.MANIKUMAR

&

THE HONOURABLE MR. JUSTICE SHAJI P.CHALY

Monday, the 9th day of November 2020/18th Karthika, 1942

WP(C) No.28250/2017(S)

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 KARUMKIL HOUSE, KUNDANNOOR P.O, THRISSUR DISTRICT-680 590).

RESPONDENTS

1. 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 IMPEADED

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 IMPEADED 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 27/10/2020  
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:

P.T.O.

S. MANIKUMAR, CJ  
&  
SHAJI P. CHALY, J

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W.A. No. 2151 of 2017  
and  
W.P(C). No. 28250 of 2017(S)

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Dated this the 9<sup>th</sup> day of November, 2020

ORDER

S. Manikumar, CJ.

Pursuant to our statutory notice, Mr.Rajan Khobragade, Principal Secretary to Government, Health and Family Welfare Department appeared before us and fairly admitted that there is some delay in implementing the directions of this Hon'ble Court dated 5.10.2020, which was brought to his notice on 13.10.2020. He submitted that thereafter a meeting was convened at the highest level and accordingly on 9.11.2020 a sum of Rupees Fifty Lakhs has been deposited in the special account created for treatment of children affected with rare diseases.

2. Mr.Rajan Khobragade, Principal Secretary to the Government, Health and Family Welfare Department further submitted that utilization of the amount under the special account would be monitored and appropriate comprehensive order would be issued so as to enable the children to avail the treatment, as per the advice of the Doctors. He also submitted that expenses for treatment of two children are incurred by the Government.

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3. Mr.Rajan Khobragade, Principal Secretary to the Government, Health and Family Welfare Department submitted that steps are to be taken for the purpose of obtaining licenses of the drugs covered by National Policy and for the reduction of the cost of drugs. Mr. Ranjith Thampan, learned Additional Advocate General made submissions on the above.

4. Submission of the Principal Secretary, Health and Family Welfare Department on the aspect of delay is accepted. However, as regards the steps to be taken for licensing and for reduction of the cost of drugs, the State Government may take out appropriate applications, which would be considered on its merits.

5. Mr.Adithya Rajeev, learned counsel for the petitioner submitted that there is some technical difficulty for the lawyers in depositing the amount in the Special Account through online payment. Learned counsel for the petitioner is directed to submit details of the difficulties/deficiencies to the Principal Secretary to the Government, Health and Family Welfare Department, Thiruvananthapuram and that the latter shall take steps to cure the same, to enable deposits.

6. Bharat Petroleum Corporation Corporation, Indian Oil Corporation, and Hindustan Petroleum Corporation have filed their respective statements, which are extracted hereunder:

"STATEMENT FILED ON BEHALF OF BHARAT  
PETROLEUM CORPORATION LTD.

This statement is filed pursuant to the directions of this Hon'ble Court and in pursuance of the Order dated 27.10.2020, directing the Oil Marketing Corporations to take appropriate decisions on providing necessary funds for treatment of children affected with rare diseases.

This statement is filed for the limited purpose of bringing on record, the instructions as received from Bharat Petroleum Corporation Ltd. The Corporation craves leave to file a detailed counter affidavit at a later stage, if required.

At the outset, it may be noted that as part of Corporate Social Responsibility, BPCL takes up only specific 'Projects' for implementation. For this, the Project Implementing Agency has to submit a proposal consisting of;

- a. Specific objective of the project
- b. Methodology mentioning mechanism for implementation of programme and plan of execution
- c. Target Group Monitoring mechanism
- d. Outcome/result expected
- e. Detailed estimate
- f. Payment schedule
- g. Sustainability plan.

Only such proposal are considered by the concerned CSR Committee and approved. Therefore, in order for BPCL to be able to consider making contributions to the instant cause, the Kerala State Legal Services Authority has to submit a specific project proposal with plans about the sustainability of the project. Submission of said proposal has to conform to a stipulated format. A true copy of the format for submission of

project proposal is produced herewith and marked as Annexure A, for identification.”

STATEMENT FILED ON BEHALF OF INDIAN OIL  
CORPORATION LTD.

This statement is filed pursuant to the directions of this Hon'ble Court and in pursuance of the Order dated 27.10.2020, directing the Oil Marketing Corporations to take appropriate decisions on providing necessary funds for treatment of children affected with rare diseases.

This statement is filed for the limited purpose of bringing on record, the instructions as received from Indian Oil Corporation Ltd (hereinafter, 'IOCL'). The Corporation craves leave to file a detailed counter affidavit at a later stage, if required.

At the outset, it may be noted that IOCL focuses its CSR efforts on projects of a sustainable and capital nature, beneficial to society at large, as opposed to those focused on particular individuals/target groups. One-off events, charitable contributions are not under the ambit of IOCL's CSR projects. As per the CSR Policy of IOCL, the parameters for contribution of funds are as follows:

1. The proposed project must be approved by the Board, on the recommendation of Board Committee, as per Schedule-VII / CSR Rules.
2. Contribution must be made into a corpus of a Trust, Society, Section-8 Company, etc., as long as
  - (a) the Trust, Society, Section-8 Company, etc. have been created exclusively for undertaking CSR activities or
  - (b) the corpus is created exclusively for a purpose directly

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relatable to a subject covered in Schedule-VII.

3. Availability of budget.

Upon meeting the above criteria, IOCL further requires the following for approval and sanction of the budget.

1. A request directly from the party with the proposal (this is ideally from the concerned Government official) seeking CSR financial assistance
2. Estimated cost and basis for the estimate
3. Details of executing agency and method of selection
4. Method/reasons of selection of particular beneficiaries among many eligible cases.
5. Records on how the fund is planned to be utilized
6. Confirmation on future maintenance of such corpus by the beneficiary/ Institution/ Stakeholders without any further implication to IOC
7. Confirmation on publicity, credits and mileage to IOC 8. Impact assessment.

Therefore, in order for IOCL to be able to consider making contributions to the instant cause, a specific project proposal has to be submitted which includes details regarding plans about the sustainability of the project.

IOCL earmarks 2% of the average of its net profits earned during three immediately preceding financial years as 'S&CSR budget.' However, this expenditure is already incurred by IOCL, Pan-India for the current year. On account of the same, no contributions can be made by the Corporation, at present. The budget would be available from the beginning of the next financial year."

"STATEMENT FILED ON BEHALF OF HINDUSTAN

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PETROLEUM CORPORATION LTD.

This statement is filed pursuant to the directions of this Hon'ble Court and in pursuance of the Order dated 27.10.2020, directing the Oil Marketing Corporations to take appropriate decisions on providing necessary funds for treatment of children affected with rare diseases.

This statement is filed for the limited purpose of bringing on record, the instructions as received from Hindustan Petroleum Corporation Ltd. The Corporation craves leave to file a detailed counter affidavit at a later stage, if required.

Pursuant to much deliberation, Hindustan Petroleum Corporation Ltd. is unfortunately not in a position to contribute funds to the Lysosomal Support Society as large amounts of CSR contributions have already been made on account of COVID-19 related activities across India. On account of such paucity of funds, the Corporation does not have the capacity to make contributions in this financial year.”

Oil Corporations are directed to finalise proposals averred.

7. Taking note of the steps taken by the Kerala Legal Services Authority and the need to provide sufficient funds for the continuous treatment of children affected with rare diseases, we would deposit a sum of Rs.25,000/- each to the credit of Special Account created for the treatment.

8. We are satisfied with the oral explanation offered by the

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Principal Secretary to the Government, Health and Family Welfare Department for the delay in implementing the orders of this Court. Taking note of the personal appearance and the COVID-19 Pandemic situation, we are of the view that no affidavit is required to be filed for dispensing with future appearance of Principal Secretary to the Government, Health and Family Welfare Department. Future appearance is dispensed with.

Post on 9.12.2020.

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

/true copy/

*Jayalitha*  
13.11.2020  
ASSISTANT REGISTRAR

SOU.

*[Signature]*  
13/11/20.