

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

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

Dated this the 7th day of August, 2020

ORDER

S. Manikumar, CJ

On this day, when the matter came up for hearing, Mr.Arjun Raghavan, learned counsel for the petitioner submitted that there are 16 children, who require treatment for various rare diseases.

2. By inviting attention of this Court to communication dated 6.8.2020 issued on behalf of Principal Secretary to Government, Health & Family Welfare (FW) Department, Thiruvananthapuram, Mr.M.R. Sabu, learned Senior Government Pleader submitted that the Managing Director, Kerala Medical Services Corporation, Thiruvananthapuram has been addressed to take up follow up action and comply with the direction of this Court dated 5.8.2020 and furnish a report at the earliest.

3. Mr. M. Ajay, learned counsel appearing for Kerala Medical Services Corporation Ltd., Thiruvananthapuram submitted that a copy of this order has been communicated for immediate action.

4. However, Mr. Sunil Shankar, learned counsel for SANOFI GENZYME, 6th respondent submitted that in India, the respondent is

providing financial assistance for treatment of 133 children, who suffer from rare diseases.

5. In Kerala, nine children are affected with Pompe disease and seven are provided with financial assistance by SANOFI GENZYME, the 6th respondent. State has to support the treatment only for two children. Mr. Sunil Shankar, learned counsel for the 6th respondent further submitted that as on today, medicines are available in Mumbai. Kerala Medical Services Corporation Ltd., has not placed any orders for supply.

6. . In our interim order, we have already indicated that request to be made forthwith. We hope the Managing Director, Kerala Medical Services Corporation Ltd., Thiruvananthapuram will take immediate action as ordered.

7. The Principal Secretary, Health & Family Welfare Department is directed to disburse necessary funds for the purpose of securing medicines from the 6th respondent. This should be done forthwith.

8. On receipt of request from the Managing Director, Kerala Medical Services Corporation Ltd., Thiruvananthapuram, 6th respondent is directed to supply the medicines to enable continuation of treatment. Medicines be sent to the respective hospitals by the concerned.

9. Kerala Legal Services Authority has filed its report dated

6.8.2020, setting out the steps taken by the Authority to generate resources to facilitate treatment. Inasmuch as physical meeting was arranged, there is no participation.

10. KeLSA is directed to explore the possibility of video conferencing with the Corporate Sector/Banks and others. KeLSA appears to have requested for preparation of a short film for screening. At present, theaters are closed. In such circumstances, KeLSA is directed to issue an advertisement in press/visual media, for contribution from public/NGOs and others.

11. On our request, Mr. E.K. Nandakumar, learned Senior Counsel representing some of the Oil Companies and public sector undertakings is present today. He is requested to interact with the Secretary, Kerala Legal Services Authority and the Regional Heads of Oil Companies/public sector undertakings, for contribution of funds in the specific head of account created by the State Government for providing treatment to children affected with rare diseases. Head of Account is as hereunder:

Name of the Bank and Address: State Bank of India,
Trivandrum city (70028), P.B.No.22,
M.G.Road, Statue-695 001.

Account No. 3922992468 – 4
IFS Code SBIN0070028.

12. Mr. Sunil Shankar, learned counsel appearing for SANOFI GENZYME, the 6th respondent, who is also appearing for the Indian Overseas Bank has volunteered that he would appraise the Bank Authorities for the above said cause. There are many NGOs and other charitable institutions, who may be willing to contribute. Public may also be willing to contribute. They might address the cause of the children and treatment.

13. We also request the Registrar General, High Court of Kerala, to take necessary steps, as to whether the press/visual media would make necessary awareness/advertisement, for raising finance assistance and consequently, deposit the same in the specific account created by the State Government for the purpose of treatment for the children affected with rare diseases.

14. Mr. M.R. Sabu, learned Senior Government Pleader appearing for 2nd respondent and Mr. M. Ajay, learned standing counsel appearing for Kerala Medical Services Corporation (4th respondent) shall communicate the orders of this Court today itself, for compliance in letter and spirit.

15. Registry is directed to furnish a copy of this order to Mr. E.K. Nandakumar, learned Senior Counsel appearing on behalf of the Oil Companies/public sector undertakings. Registry is also directed to

W.A.2151/2017 & W.P(C).28250/2017

5

show the name of Mr. M. Gopikrishnan Nambiar, as the learned counsel representing the Oil Companies/public sector undertakings.

Post on 14.8.2020.

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

/true copy/

Jayalalitha
10-8-2020
ASSISTANT REGISTRAR

SOU.

R
10/8/20

10/8/20