

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

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

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

Dated this the 10th day of March, 2022.

ORDER

S. MANIKUMAR, CJ.

On 26th July, 2021, we ordered thus:

“On this day, when the matter came up for hearing, based on G.O. (Rt) No. 480/2021/SJD dated 20.07.2021, issued for sanctioning of deposited amount of Rs. 50,00,000/-, to the credit of the special account created for treatment of children with rare diseases, Mr. M. R. Sabu, learned Senior Government Pleader, submitted that on 23.07.2021, Government have credited Rs. 50,00,000/-. G.O. (Rt) No. 480/2021/SJD dated 20.07.2021 is reproduced:-

“GOVERNMENT OF KERALA

Abstract

**Social Justice Department - Kerala Social Security Mission -
Transfer and deposit an amount of Rs 50 Lakh from "We Care"
Account to the Special account created for the treatment of
children with rare diseases - Sanction accorded - Orders issued.**

SOCIAL JUSTICE (C) DEPARTMENT

G.O.(Rt)No.480/2021/SJD Dated, Thiruvananthapuram, 20/07/2021

Read 1 G.O(Rt) No 3001/2018/H&FWD dated 29/9/2018

- 2 Order dated 20/1/2021 in W.A No 2151 of 2017 of Hon'ble High Court of Kerala
- 3 Order dated 13/7/2021 in I.A No.1/2021 in W.A No 2151 of 2017 of Hon'ble High Court of Kerala
- 4 Note No 470/FW2/2016/H&FWD dated 19/7/2021 from Principal Secretary, H&FWD

ORDER

As per the Government Order read as first paper above a corpus fund to the tune of Rs 50 Lakh was set up in Kerala Social Security Mission and that amount was released to the account of Principal Secretary, H&FWD towards the corpus fund for the treatment of children suffering from rare diseases.

2) As per order dated 20/1/2021 of the Hon'ble High Court of Kerala read as 2nd paper above has ordered the first and second respondent ie, Chief Secretary and the Principal Secretary to Government, H&FWD, to contribute a sum of Rs 50 Lakh annually to the special account created for the treatment of children with rare diseases, within a period of one month from the date of receipt of a copy of the order.

3) As per order dated 13/7/2021 of the Hon'ble High Court of Kerala read as 3rd paper above, it was ordered, the Principal Secretary to Government, H&FWD, to deposit the amount and to compliance report by 22/7/2021. The Principal Secretary, H&FW Dept has requested to instruct all concerned to take urgent steps for depositing Rs 50 Lakh from the WE CARE scheme to the special account created for the treatment of children with rare diseases.

4) In the above circumstances, sanction is accorded to the Executive Director, Kerala Social Security Mission to transfer and deposit an amount of Rs. 50 Lakh from We Care Account of Kerala Social Security Mission to the special account created in the name of Principal Secretary, Health & Family Welfare for treatment of children with rare diseases subject to condition that the amount shall be recouped through additional authorization to KSSM under the Head of Account 2235-60-200-72(7)(vayomithram).

(By order of the Governor)

Nisha S.

Additional Secretary”

2. Deposit made on 23.07.2021 is placed on record.

3. Mr. A. Rajagopal, learned counsel for the Central Government, submitted that policy of the Government is not to extend financial assistance for all the rare diseases. However, a sum of Rs. 20,00,000/- is allocated for diseases, which require one time treatment. He further added that Central Government have already taken up the steps for creating a portal for crowd funding.

Learned counsel for the Central Government is directed to file a statement on the instructions received.”

2. Pursuant to the above, the State Government has filed a statement of affidavit dated 4th March, 2022, wherein, it is stated that the Kerala Social Security Mission has issued a work order to an agency, namely, Global Innovative Technologies for generating

awareness towards mobilisation of funds for 'We Care Project', through social media.

3. Earlier, in our orders, we have already explained the projects undertaken by the State Government under the head 'We Care Project', for mobilising funds for the treatment of various diseases, expenses for marriages, educational grants etc. and also made it clear that 'We Care Project' was not focused on the treatment for rare diseases and in such circumstances, we directed the Government to create a special account in the name of the Principal Secretary, Health and Family Welfare Department, Government of Kerala, in the State Bank of India, Trivandrum Branch, for generating a corpus for the children suffering from rare diseases and accordingly, a special fund has been created.

4. From the statement dated 4th March, 2022 of the State Bank of India, Trivandrum City, it could be deduced that the balance amount, as on 01.02.2022 in the said account meant for the treatment of children suffering from rare diseases is Rs.1,14,81,381/-, raised by the State Government, which includes contribution from public, various institutions and the legal fraternity.

5. From the statement of account, it could be further seen that

apart from State Government and various institutions, certain good hearted individuals have also come forward to deposit amounts in the special account created for the purpose. We also place on record our appreciation to those individuals.

6. We are also constrained to bring it to the notice of the Government that there is no sufficient advertisement or awareness created to the general public, enabling them to contribute, with all their might, to the special account created in the name of the Principal Secretary, Health and Family Welfare Department, Government of Kerala, exclusively, for the treatment of children suffering from rare diseases.

7. Had there been sufficient advertisement/awareness, certainly, there would have been contribution from the general public. When the State Government had permitted Kerala Social Security Mission to issue a work order to an agency, namely, Global Innovative Technologies, for generating awareness towards mobilisation of funds for 'We Care Project', through social media, the Government ought to have created such awareness in the case of rare diseases also. Matter has been pending before this Court for nearly 5 years and no steps have been taken in this regard.

8. Under Article 21 of the Constitution of India, a duty is cast upon the State Government to provide treatment to the needy persons, in the case on hand children.

9. Further, medicines are supplied by the manufacturers, directly to the hospitals and some are procured by the Kerala Medical Corporation. Inasmuch as there is not much contribution from the general public and others and since the State Government is duty bound to provide adequate treatment, we direct the Principal Secretary, Health and Family Welfare Department, Thiruvananthapuram, appellant No.2, to make an advertisement in the leading English and Malayalam newspapers, so as to enable the general public aware of the existence of a special account, in the name of the Principal Secretary, Health and Family Welfare Department in the State Bank of India, for the treatment of children suffering from rare diseases.

10. Print, electronic and social media always play an important role in the people achieving their constitutional rights and therefore, we request them to create awareness among the public to contribute for the treatment of the children, suffering from rare diseases and incapacitated due to their economic status.

11. At this juncture, we also deem it fit to observe that it is a sorry state of affairs that none of the corporate companies have come forward to contribute. It is well known that the corporate sector has corporate social responsibility. Earlier, during the course of arguments, we found that the Government of India enjoyed with a duty to part their contribution for the treatment for rare diseases and accordingly, directions were issued and thus, the Central Government contributed a sum of Rs.1.5 Crores, which amount has been deposited in the special account.

12. However, clause 10 of the National Policy for Rare Diseases, 2021 ('National Policy, 2021' for short) dealing with 'Government of India support in treatment', specifies that financial support upto Rs.20 lakh under the Umbrella Scheme of Rashtriya Arogya Nidhi shall be provided by the Central Government for treatment of those rare diseases that require a one-time treatment (diseases listed under Group 1).

13. It is also stated that beneficiaries for such financial assistance would not be limited to BPL families, but extended to about 40% of the population, who are eligible as per norms of Pradhan Mantri Jan Arogya Yojana, for their treatment in Government tertiary

hospitals only.

14. It is further stated therein that State Governments can consider supporting patients of such rare diseases that can be managed with special diets or hormonal supplements or other relatively low cost interventions (Diseases listed under Group 2).

15. It is further stated therein that keeping in view the resource constraints, and a compelling need to prioritize the available resources to get maximum health gains for the community/population, the Government will endeavour to create alternate funding mechanism through setting up a digital platform for voluntary individual and corporate donors to contribute to the treatment cost of patients of rare diseases. In the above context, it is profitable to extract clause 10, which reads thus:

“10. Government of India support in treatment

The following initiatives shall be taken for patients of Rare Diseases:

i. Financial support upto Rs. 20 lakh under the Umbrella Scheme of Rashtriya Arogya Nidhi shall be provided by the Central Government for treatment, of those rare diseases that require a one-time treatment (diseases listed under Group 1). Beneficiaries for such financial assistance would not be limited to BPL families, but extended to about 40% of the population, who are eligible as

per norms of Pradhan Mantri Jan Arogya Yojana, for their treatment in Government tertiary hospitals only.

ii. State Governments can consider supporting patients of such rare diseases that can be managed with special diets or hormonal supplements or other relatively low cost interventions (Diseases listed under Group 2).

iii. Keeping in view the resource constraints, and a compelling need to prioritize the available resources to get maximum health gains for the community/population, the Government will endeavour to create alternate funding mechanism through setting up a digital platform for voluntary individual and corporate donors to contribute to the treatment cost of patients of rare diseases.

iv. Voluntary crowd-funding for treatment

Keeping in view the resource constraint and competing health priorities, it will be difficult for the Government to fully finance treatment of high cost rare diseases. The gap can however be filled by creating a digital platform for bringing together notified hospitals where such patients are receiving treatment or come for treatment, on the one hand, and prospective individual or corporate donors willing to support treatment of such patients. The notified hospitals will share information relating to the patients, diseases from which they are suffering, estimated cost of treatment and details of bank accounts for donation/ contribution through online system. Donors will be able to view the details of patients and donate funds to a particular hospital. This will enable donors

from various sections of the society to donate funds, which will be utilized for treatment of patients suffering from rare diseases, especially those under Group 3. Conferences will be organised with corporate sector companies to motivate them to donate generously through digital platform. Ministry of Corporate Affairs will be requested to encourage PSUs and corporate houses to contribute as per the Companies Act as well as the provisions of the Companies (Corporate Social Responsibility Policy) Rules, 2014 (CSR Rules). Promoting health care including preventive health care is included in the list in the Schedule for CSR activities. Treatment cost of the patient will be first charge on this fund. Any leftover fund after meeting treatment cost can be utilized for research purpose also.”

16. According to the learned counsel for the petitioner, children in the instant writ petition are suffering from rare diseases falling under Group 3(3a) under clause 6 of the Policy, which requires treatment continuously. In the said circumstances, we direct the Union of India, represented by its Secretary, Health and Family Welfare Department, 4th respondent in the writ appeal, to address the issue, taking note of the expenses involved to extend financial support to the treatment of the children falling under Group B(a).

17. Yet another factor which could be gathered from clause 10 is that a financial support upto Rs.20 lakhs under the Umbrella Scheme of Rashtriya Arogya Nidhi is extended for the treatment of those rare

diseases that require a one-time treatment (diseases listed under Group 1). Therefore, we are of the considered view that when there are so many rare diseases categorized in each group, the Central Government ought to have considered the case of financial support to those who are suffering from rare diseases that may require more than one time treatment and the consequential expenses also. We hope that the Government will address the issue as well.

18. National Policy, 2021 permits voluntary crowd funding for treatment. However, the said funding can be made only to the Centres of Excellence. During the course of hearing, we were informed that there are 8 Centres of Excellence for treating the patients suffering from rare diseases.

19. Clause 14 of the National Policy, 2021 deals with 'implementation strategy' and as per clause (vi), the Government shall notify selected Centres of Excellence at premier Government Hospitals for comprehensive management of rare diseases. The Centres of Excellence will be provided one time grant subject to a maximum of Rs. 5 crore each for infrastructure development for screening, tests, treatment, if such infrastructure is not available.

20. As per clause (x) of clause 14, State Governments will be

requested to create Department of Medical Genetics at least in one medical college in the State for imparting education and increasing awareness amongst health care professionals.

21. At this juncture, attention of this Court was invited to clause (ix) dealing with 'Centres of Excellence (COE) and Nidan Kendras' and clause 9(1) states that the Government will notify selected Centres of Excellence, which will be the premier Government Tertiary Hospitals with facilities for diagnosis, prevention and treatment of rare diseases. The institutes that would be notified as Centers of Excellence for Rare Diseases are as follows:

- a) All India Institute of Medical Sciences, New Delhi
- b) Maulana Azad Medical College, New Delhi
- c) Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow
- d) Post Graduate Institute of Medical Education and Research, Chandigarh
- e) Centre for DNA Fingerprinting & Diagnostics with Nizam's Institute of Medical Sciences, Hyderabad
- f) King Edward Medical Hospital, Mumbai.
- g) Institute of Post-Graduate Medical Education and Research, Kolkata
- h) Center for Human Genetics (CHG) with Indira Gandhi Hospital, Bengaluru

One of the Government Hospitals among the Centres of Excellence near to the State of Kerala is the Center for Human Genetics (CHG) with Indira Gandhi Hospital, Bengaluru.

22. Right from the beginning, it is the contention of the learned counsel for the petitioner that of the twelve children, two of them despite treatment died and that they are taking treatment from the Government Hospitals in Kerala. Going through the National Policy, 2021, we find that the above said institutes having notified as Centres of Excellence are for the treatment of rare diseases and further, a Premier Government Tertiary Hospital should also be sufficiently equipped to treat the rare diseases.

23. In that context, the Principal Secretary, Health and Family Welfare Department, Government of Kerala, has addressed by Annexure 13 letter dated 02.12.2021 to the Secretary, Ministry of Health and Family Welfare, Government of India, to take urgent necessary action to include Government Medical College Hospital, Thiruvananthapuram, Government Medical College Hospital, Kottayam and Government Medical College Hospital Kozhikode as Centres of Excellence in the list of hospitals for treatment of rare diseases under National Rare Disease Policy.

24. As stated supra, the above said hospitals are providing treatment to the children. As per clause 9(1) of the National Policy, 2021, what is required to notify a hospital as Centre of Excellence is

that such hospital should be of Premier Government Tertiary Hospital having facilities for diagnosis, prevention and treatment of rare diseases.

25. We are of the view that the abovesaid hospitals should have advanced technology to provide treatment to the children suffering from rare diseases. Attention of this Court was also invited to the suggestion for improvising the hospitals by inclusion of various equipments which may be required for the treatment of rare diseases.

26. Further, funding has been permitted only in respect of certain Centres of Excellence notified. If the Principal Secretary to Government, Health and Family Welfare Department, Government of India, New Delhi, respondent No. 4 in the writ appeal, takes a favourable decision, on the request made by the State Government in respect of the hospitals stated supra, children and others suffering from rare diseases could be treated within the State of Kerala and there could be sufficient contribution from the Government of India as well.

27. In the light of the above observations, we direct the Secretary to the Government, Health and Family Welfare Department, Government of India, New Delhi, respondent No. 4 to consider Annexure 13 letter dated 02.12.2021 and take appropriate decision expeditiously. Annexure 13 letter dated 02.12.2021 is reproduced hereunder:

Annexure 2

GOVERNMENT OF KERALA
PRINCIPAL SECRETARY



Health & Family Welfare Department
Government of Kerala
Thiruvananthapuram-695 001
Office : 0471-2327003
Phone : 0471-2510255
Fax : 0471-2327865
E-mail : pkeralhealth@gmail.com

Annexure 13

D.O.No:HEALTH-FW2/114/2021-HEALTH Dated: 02/12/2021

Dear Sir,

Please refer your DO letter no W-11037/41/2021-Grants (RD) dated 15/11/2021 wherein it was informed that the Ministry of Health & Family Welfare has written to ASG, Kerala High court for impleading MoHFW as additional respondent in WP(C) 7984/2021 so that an appropriate application could be filed in Kerala High Court in compliance of the order dated 20/09/2021 of Hon'ble Delhi High Court in WP No.5315/2020-Master Arnesh Shaw Vs. UOI & others. It is also informed that the Hon'ble Kerala High Court had directed MoH&FW to take necessary steps to ensure that the funds to the tune of ₹ 63 Crores collected from the general public for the treatment of a person suffering from a Rare Disease who unfortunately expired, are utilized for treatment of the present petitioners and other similarly placed patients under the National Policy for rare Diseases 2021.

Further it is stated that State Govt. shall advise all that instead of collecting funds through individual platforms /online portals, the "Digital portal for Crowd funding & Voluntary Donations for Patients of Rare Diseases" of the Central government may be utilized for collecting funds for providing financial support to the patients suffering from rare diseases and the platform has the facility of collection of funds patient wise and Centre of Excellence wise.

In this connection, I would like to bring your attention to the Office memorandum No.W.12014/08-Grants dated 30/03/2021, wherein National Policy of Rare Diseases was formulated Govt. of India have notified only 8 institutions in the country as Centre of Excellence for managing patients suffering from rare diseases and mentioned that more COEs can be added for regional outreach if they are found suitable in terms of infrastructure and human resources based on recommendations of Technical Committee. Unfortunately no hospitals from Kerala are seen included in the list. A patient from Kerala suffering from rare diseases have to go either to Bangalore or to Hyderabad searching for a COEs which is quite difficult for them at that pathetic situations. You are well aware that Kerala have well established health care systems and GOI already appreciated its vast development in the Health Sector. The Primary, Secondary and Tertiary Health care centres File No.HEALTH-FW2/114/2021-HEALTH developed all over Kerala is appreciated not

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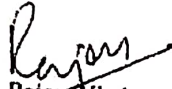
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only by GOI but also by World Renowned forums. Doctors working in our medical institutions are highly experienced and they are also highly dedicated in the field. Almost all our hospitals especially Medical Colleges have all infrastructure facilities and sufficient human resources for handling all types of patients. In that circumstances that I have requested you vide my DO letter No FW2/470/2016/Health dated 07/10/2021 to take urgent necessary action to include Government Medical College Hospital, Thiruvananthapuram, Government Medical College Hospital Kottayam and Government Medical College Hospital, Kozhikode as Centre of Excellence in the list of hospitals for treatment of rare diseases. But no reply in this regard has been received so far. Considering the observations of Honorable High Court of Kerala also in this regard I would request you to bestow your personnel attention in this regard and take urgent steps to include the above hospitals in the list of COEs under National Rare Disease Policy.

With Best Wishes

Sincerely,


Rajan Khobragade

Shri. Rajesh Bhushan IAS,
Secretary,
Ministry of Health & Family Welfare,
Government of India

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28. Respondents shall file a statement of facts responding to the observations, directions and the decision to be taken by the Central Government. Action to implement the directions regarding advertisements through print, electronic and social media be reported to this Court within two weeks.

Post the matter after two weeks.

sd/-

**S. MANIKUMAR,
CHIEF JUSTICE.**

sd/-

**SHAJI P. CHALY,
JUDGE.**

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