

HIGH COURT OF MADHYA PRADESH

Writ Petition No. 18974/2018

(Prajwal Shrikhande Vs. State of M.P. and others)

(PRESENT : HON. SMT. NANDITA DUBEY, J (THROUGH VIDEO CONFERENCING))

Jabalpur, Dated :22.06.2020

Shri Nikhil Tiwari, learned counsel for the petitioner.

Shri Vivek Sharma, learned Dy. Advocate General for the
for the respondent/State.

Shri Vikram Singh, learned counsel for respondent
No.2/Union of India.

Shri Richard Rahul Rajoor, learned counsel for respondent
No.4/NHM.

I.A. No.388/2020, which is an application for summoning
of progress report is dismissed as not pressed.

Application for urgent hearing is allowed.

On account of the prevailing conditions worldwide,
brought about by the COVID 19 virus, I.A. No.4246/2020, an
application for further interim directions has been heard and
decided through video conferencing, to maintain social
distancing. The necessary parties have effectively been
represented by their respective counsels through video
conferencing.

This application is filed by the petitioner to direct the respondents No. 1 to 4 to extend the financial assistance so as to enable him to continue the treatment of his four years old son, who is suffering from a rare disease "Gaucher".

Earlier by way of interim arrangement, National Health Mission has agreed to help out with the 40% of the cost of the treatment for its own funds, 33% of the cost was agreed to be borne by the Company and the petitioner has agreed the rest of 27% from his own resources. Accordingly an interim order was passed on 14.02.2019.

Learned counsel for the petitioner submits that petitioner's 4 years old son is suffering from a life threatening rare disease "Gaucher" for which his son is required to undergo an Enzyme Replacement Therapy (ERT) every 14 days to save his life. The last infusion took place on 17.06.2020, he missed one vial. If the vial is not administered timely, it may be fatal to the petitioner's son. He further submits that earlier in compliance of order dated 14.02.2019, National Health Mission has provided 40% cost as financial assistance and he has arranged 27% from his own resources. However, this is not a one time problem, but requires a life long treatment. The cost of treatment is prohibitive and under the present Covid 19

situation, the petitioner is unable to arrange for any more funds. It is submitted that earlier the Central Government had made a statement at Bar that the National Policy for Treatment for Rare Diseases, 2020 shall be finalized within nine months, but nothing has been done so far. Period of one year has passed and the petitioner requires further assistance for arranging the medicine (vials) for the Enzyme Replacement Therapy. It is further submitted that the cost of treatment is progressively increases, two to three lacs per kg with the corresponding increase of the weight of the child. As of today, Rs.59 lacs is required for the treatment of petitioner's son.

It is stated in the affidavit filed by the respondent No.2/Union of India that the policy of 2017 cannot be implemented and kept in abeyance vide Non-statutory Gazette Notification dated 18.12.2018, till the policy is revised. Shri Vikram Singh, learned counsel appearing on behalf of respondent No.2/ Union of India has urged that the draft of National Policy for Rare Diseases, 2020 has been finalized and placed on website of the Ministry of Health and Family Welfare inviting comments/views of the stakeholders including States and Union Territories and the general public. However, the State of M.P. has neither shown any interest nor communicated with the Centre in this regard. It is stated that under the

scheme of Rashtriya Arogya Nidhi (RAN), one time financial assistance is provided to the patients belonging to the families living below poverty line. Gaucher is not covered under the list of rare diseases eligible for assistance under the Rashtriya Arogya Nidhi (RAN). Learned counsel further submits that at present there is no scheme under which financial assistance on recurring basis can be provided for treatment of rare diseases like MPS, Gaucher, etc., which incurred exorbitant cost. It is stated that Public Health and Hospitals is a state subject and unless new policy is finalized and implemented, no financial assistance can be extended to the State Government or petitioner in this matter.

Shri Richard Rahul Rajoor, learned counsel for respondent No.4/NHM has submitted that National Health Mission has already helped out with 40% of the approved cost of treatment of petitioner's son and complied with the order dated 14.02.2019. It is submitted that Rashtriya Arogya Nidhi (RAN) provides only one time financial assistance to the persons below the poverty line. Present petitioner does not come under the category of BPL, further one time assistance has already been provided to the petitioner in the light of interim order. It is submitted that vide e-mail dated 30.05.2020 (Annexure R-4-3) pending revision of the national policy under the umbrella

scheme of Rashtriya Arogya Nidhi (RAN), a component for treatment of rare diseases has been included with effect from 01.01.2019 for providing one time financial assistance to patients below the poverty line and an amount of Rs.100 crores has been associated for rare diseases component of umbrella scheme of Rashtriya Arogya Nidhi (RAN) 2019-2020. According to this policy, share of treatment will be borne between the Centre and State in the ratio of 60:40. Learned counsel further submitted that answering respondent has already released 40% pursuant to the direction of this Court, however, the Centre or State has not released its remaining 60% share.

The stand of Central Government is that the State Government has not communicated its view with regard to the draft policy and unless a new policy is finalized and implemented, no financial help can be extended to the petitioner. According to Shri Vikram Singh, (counsel for respondent No.2), it is for the State Government to ensure that necessary funds are made available for treatment of such patients with rare diseases. Further, as per the stand of respondent No.4, they have already provided 40% financial assistance under Rashtriya Arogya Nidhi (RAN) and rest 60% is to be provided by the Centre in view of the e-mail dated 30.05.2020.

Petitioner's 4 years old son is suffering from rare genetic disorder called "Gaucher". In order to survive, he has to undergo the Enzyme Replacement Therapy every 14 days. This treatment is very costly and continuous financial assistance is required for ensuring that the treatment is not interrupted. Petitioner's son has already missed one vial on 17.06.2020, if timely treatment is not given, it may prove fatal to his health.

Fundamental rights guaranteed under Article 21 of the Constitution of India also incorporates right to health. It is the corresponding obligation of Centre as well as the State Government to ensure that fundamental rights guaranteed under Article 27 of the Constitution of India is not violated. This aspect has already been considered by the Supreme Court as well by the different High Courts and direction has been given to the State as well as Central Government to release funds for the treatment of patients suffering from rare diseases. The Central Government cannot shy away from its responsibilities on the ground that draft policy has not been finalized due to the non-corporation of M.P. State Government. It is for both the governments to resolve the matter amicably, especially when both the governments are ruled by the same party. As the State or Centre was not coming forward to bear the

responsibility, the respondent No.4/NHM on humanitarian grounds has already released 40% of the treatment cost as its share under the Rashtriya Arogya Nidhi (RAN) policy, the Central Government is, therefore, required to immediately release its 60% share under the said policy.

I am aware that release of the 60% by the Central Government under the Rashtriya Arogya Nidhi (RAN) policy will not be enough for the continuous treatment of petitioner's son for the entire year. Hence, following interim directions are required to be passed :-

- (i) The Central Government is directed to immediately pay the 60% of the cost of treatment of petitioner's son as its share under the Rashtriya Arogya Nidhi (RAN) policy.
- (ii) The State Government is directed to pay the balance of the amount, 40% or more required for the continuous and uninterrupted treatment of petitioner's son for a period of one year.
- (iii) The State Government will be at liberty to recover the contribution from the Centre as per the share allocation after the National Policy for Rare Diseases, 2020 is finalized.

- (iv) The Central Government is directed to finalize and implement the National Policy for Rare Diseases, 2020 within a period of six months as of today.
- (v) While finalizing the 2020 policy, it shall be borne in mind that rare diseases like Gaucher etc. require continuous financial assistance for continuous and uninterrupted treatment and "One Time Financial Assistance" and requirement of being "Below Poverty Line" cannot be made a condition for grant of financial assistance, as disease does not seek a child/person on the basis of his/her financial ability or economic condition.
- (vi) The Central and State Government shall file an affidavit of compliance by 15th of July, 2020. Copy of which shall be served to all concerned parties.
- (vii) In the event, the amount as directed under this order is not released on time by the Central and the State Government, it will be open to the petitioner to move this Court for seeking appropriate directions.

I.A. No.4246/2020 stands disposed of.

List this matter on 20.07.2020.

Certified copy/e-copy as per rules/directions.

**(Nandita Dubey)
Judge**