

**THE HIGH COURT OF JUDICATURE FOR MADHYA  
PRADESH AT JABALPUR**

(Division Bench)

**Writ Appeal No.16/2021**

State of Madhya Pradesh and others .....Appellants

Versus

Prajwal Shrikhande and another .....Respondents

**Coram**

**Hon'ble Shri Justice Mohammad Rafiq, Chief Justice  
Hon'ble Shri Justice Vijay Kumar Shukla, Judge**

**Appearance**

Shri Swapnil Ganguly, learned Deputy Advocate General for the appellants/State.

Shri Devashish Sakalkar, learned counsel for the respondent No.1/writ-petitioner.

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

**Law laid down:**

Writ Appeal arising from interlocutory orders passed by the learned Single Bench in writ petition seeking a direction to the State of Madhya Pradesh and Union of India to provide the benefit of the "National Policy for Treatment of Rare Diseases" to the son of the petitioner suffering from rare disease "Gaucher". The orders under challenge in writ appeal required the State Government to pay entire amount for treatment of such disease with a further direction to the Central Government to finalise the new policy and with liberty to the State Government to recover the amount from the Central Government. – **Held** - "Right to Health" is one of the facets of the Right to Life under Article 21 of the Constitution of India. Therefore, it is the duty of the Central Government and the State Government to protect the life of citizen, especially the children of the tender age suffering from rare disease. Accordingly, the order dated 15.12.2020 passed by the learned Single Bench is set aside and appeal allowed in part with direction to the Central Government and the State Government both to bear the cost of the treatment of the child in proportion of 60:40, till finalization of the New Policy.

Reference made to:

*Navtej Singh Johar Vs. Union of India (2018) 10 SCC 1*

*Union of India Vs. Moolchand Kharaiti Ram Trust (2018) 8 SCC 321*

*Paschim Banga Khet Mazdoor Samiti Vs. State of West Bengal (1996) 4 SCC 37.*

*Pt. Parmanand Katara Vs. Union of India (1989) 4 SCC 286*

*Article 25 of the Universal Declaration of Human Right.*

*Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR)*

*Article 24 of the Child Rights Convention (CRC)*

The Protection of Human Rights Act, 1993.

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**Significant Paragraphs:-15 to 25**

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Hearing convened through Video Conferencing:

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## **JUDGMENT**

(27.01.2021)

**Per: Mohammad Rafiq, C.J.:**

1. This writ appeal under Section 2(1) of the M.P. Uchcha Nyayalaya (Khand Nyayapeeth Ko Appeal) Adhiniyam, 2005 has been filed by appellants State of M.P. & others challenging the order dated 22.6.2020 (Annexure WA/1) and the order dated 15.12.2020 (Annexure WA/2) passed by the Single Bench in Writ Petition No.18974/2018 filed by respondent No.1 Prajwal Shrikhande.

2. Respondent No.1/writ petitioner approached this Court challenging the order dated 23.7.2018 (Annexure P/1) passed by the Mission Director, RBSK, NHM, Bhopal and seeking a direction to the respondents i.e. State of M.P. and Union of India to provide benefit of the “National Policy for Treatment of Rare Diseases” (Annexure P/2) to the son of the petitioner named Master Harshal Shrikhande, aged 4 years.

3. Case of the respondent No.1/writ petitioner before the learned Single Judge was that his son is suffering from rare disease named “Gaucher”. The Central Government, Ministry of Health and Family Welfare promulgated a policy known as “National Policy for Treatment of Rare Diseases” after conducting a comprehensive study with the help of the experts in the field. The Central Government identified 450 rare diseases, which have been recorded in India, most

of which are serious and chronic diseases, requiring long term specialized treatment. The writ petitions were filed before the Delhi High Court by the parents of some children, who are suffering from rare diseases, contending that since the cost of treatment of such diseases is quite exorbitant, they are not covered by the insurance policy. Therefore, there is a need for formulating a national policy for treatment of the patients suffering from such rare diseases. The Delhi High Court in W.P.(C) No.4444/2016, W.P.(C) No.7730/2016 and W.P.No.7729/2016 directed the Ministry of Health and Family Welfare Department to frame a national policy for treatment of rare diseases. In compliance of the aforesaid direction, the Central Government, after taking assistance of a committee consisting of Professor V.K.Paul, Professor I.C.Verma and Dr.Deepak Tempe, formulated “National Policy for Treatment of Rare Diseases”. According to the petitioner, Gaucher disease with which his son is suffering is also identified as a rare disease. The policy envisages that the Government of India would set up a corpus of Rs.100 crores for treatment of rare diseases. It further envisages that the State Government would also contribute to such corpus. The Central Government and State Government would both contribute to the corpus in the ratio of 60:40. If the State Government wants, it can contribute larger amount to the corpus. The writ-petitioner submitted an application before the Competent Authority who however rejected the same vide order dated 23.7.2018 on the premise that he does not fall within the category of “below poverty line”.

4. Shri Devashish Sakalkar, learned counsel for the writ-petitioner has argued that petitioner's son requires doses of two vials to undergo Enzyme Replacement Therapy after every 14 days. The pharmaceutical company manufacturing the medicine made that medicine available free of cost to his son initially for 3 to 4 month. Subsequently, the company agreed to provide 1/3<sup>rd</sup> of the total medicine required for a year free of cost on the condition of payment for remaining 2/3<sup>rd</sup>. Learned counsel for the petitioner has placed reliance upon order dated 13.3.2020 passed by the Division Bench of Madras High Court in **W.P.No.21050/2017- Lysosomal Storage Disorders Vs. State of Tamil Nadu & others**, order dated 24.2.2020 passed by Karnataka High Court in **W.P.No.19061/2015- Lysosomal Storage Disorders Society in India Vs. State of Karnataka**, order dated 17.4.2020 passed by the Single Bench of High Court of Uttarakhand in **WPMS No.2312/2019- Sumit Singh Vs. Union of India and others** and the order dated 27.2.2020 passed by the High Court of Kerala in **WP(C) No.28250/2017- Lysosomal Storage Disorders Support Society Vs. State of Kerala & others**, to contend that similar matters were considered by these High Courts, which issued directions for grant of the desired relief.

5. Learned counsel for the petitioner further submitted that the Central Government having promulgated the National Policy for Treatment of Rare Diseases (Annexure P/2) was wholly unjustified in keeping the same in abeyance. It is contended that the petitioner is a practicing architect and his resources are very limited. He has a family of four members to support. He arranged money for treatment of his

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son for initial period with the help of friends and relatives and also after borrowing money from here and there but now the petitioner is unable to arrange enormous fund in this regard. According to the learned counsel for the petitioner, initially when the treatment of his son started, the cost of treatment was approximately Rs.59 lakhs for one year, reference of which is found in the letter of the Chief Medical and Health Officer, Jabalpur dated 1.1.2021 (Annexure R4-2) addressed to the Mission Director, National Health Mission, Bhopal, but now this cost has come down to Rs.45 lakhs per annum.

6. Shri Vikram Singh, learned counsel appearing for respondent No.2/Union of India submitted that subsequent to holding of the earlier policy in abeyance, a draft policy has been finalized and put in public domain for inviting objections. Once objections are received, the new policy would be notified on or before 31.3.2021. The Central Government is proposing to create a digital platform as well, where it would invite corporate sector, industrial sector and other independent firms to generously contribute to this fund. Till such policy is finalized, the Central Government cannot be required to pay or contribute anything towards financial assistance for treatment of rare disease of the son of the petitioner.

7. When the matter came up for arguments before the learned Single Judge on 14.2.2019, it was informed on behalf of the Union of India that the aforesaid policy has been kept in abeyance with effect from 18.12.2018 by a Gazette Notification and the revision of policy may take nine months. It was further informed that till the revision of the policy takes place, ad-interim Standing Finance Committee has

approved a proposal whereby under the Umbrella Scheme of Rashtriya Arogya Nidhi, a one time financial assistance of Rs.10 lakhs has been granted to those who are below poverty line. Since the petitioner does not fall in that category, the assistance could not be granted to him. The National Health Mission filed a counter affidavit before the learned Single Judge informing that the State Government vide letter dated 17.4.2018 has agreed to provide support as per the financial guidelines to the extent of 40% of the cost after the approval of Government of India. Learned counsel appearing for the Government of India then stated that there is no need for taking approval from the Government of India and the National Health Mission should be directed to provide help to the petitioner upto 40% of the approved cost. Learned counsel for the petitioner submitted that the pharmaceutical company is ready to bear 33% of the cost and for the time being, he will arrange the rest 27% from his own resources but he would still be in need for further assistance from the Central Government. The learned Single Judge vide order dated 14.2.2019 directed as an interim arrangement that till the policy of the Central Government is revised, the State will help out with the 40% as agreed. This arrangement was directed to continue till the policy is revised by the Central Government.

**8.** Pursuant to the aforesaid order dated 14.2.2019, State Government released a sum of Rs.20,80,932/- vide letter dated 28.2.2019 (Annexure WA-5). Learned counsel appearing for the National Health Mission at that stage informed the Court that assistance upto 40% of the approved cost was provided as one time

measure in view of the stipulation contained in the original policy of the Government of India but the assistance under the Rashtriya Arogya Nidhi is one time measure meant only for persons below poverty line. Since the respondent-writ petitioner does not fall within that category, he cannot be provided further assistance pending revision of the National Policy by the Central Government. The stand of the Central Government was that the State Government has not communicated its view with regard to the draft policy. Unless a new policy is finalized and implemented, no financial help can be extended to the petitioner. It is for the State Government to ensure that necessary funds are made available for treatment of patients suffering from such diseases.

9. The learned Single Judge in the order dated 22.6.2020 has observed that the fundamental right of life under Article 21 of the Constitution 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 21 of the Constitution are not violated. This aspect has been considered in various decisions by different High Courts and direction has been given to the State Government and Central Government to release the funds for the treatment of patients suffering from rare diseases. The Central Government cannot shy away from its responsibilities on the premise that draft policy has not been finalized due to non-cooperation of the State Government. Having observed thus, the learned Single Judge vide impugned order dated 22.6.2020 issued following interim directions:-

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“(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 15<sup>th</sup> 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.”

**10.** When the matter came up before the learned Single Bench on 15.12.2020, it was noted that State Government has in its reply to writ petition stated that pursuant to the order dated 22.6.2020, the State Government has further released a sum of Rs.16,23,431/- on 28.7.2020. However, the Central Government did not release any amount of its share and filed an application for recalling the order dated 22.6.2020. This application has been decided by the learned Single Judge vide order dated 15.12.2020 impugned in the present appeal. The learned Single Judge took note of the fact that so long as the petitioner was able to afford some part of treatment with the help of friends and medical companies which came forward, he did so but



now his financial resources have completely dried up. He cannot be refused help on the ground of his not belonging to BPL category. Considering that the last available dose was due for infusion on 13.1.2021, the learned Single Judge directed the State Government to provide further financial assistance required for the uninterrupted treatment of petitioner's son for next six months. The Central Government was directed to finalize the policy as soon as possible keeping in view the directions given in earlier order dated 22.6.2020. It was directed that the State Government would be at liberty to recover the amount from the Central Government as and when new policy comes into force.

11. We have given our anxious consideration to rival submissions and perused the material on record. We shall at the outset analyse the judgments of different High Courts dealing with this issue.

12. In the order passed by the Madras High Court on 13.3.2020 in **W.P.No.21050/2017-Lysosomal Storage Disorders Vs. State of Tamil Nadu & others** and connected petitions, the State Government was directed to allocate a sum of Rs.5 Crores to meet any such expenses in respect of rare diseases to such classes of patients who may be urgently requiring the same which should be disbursed and utilized by the State Government. In para 12 of the order, the Madras High Court directed the Union of India to provide one time aid to 11 patients to the tune of Rs.4.40 crores as an interim measure, as per annum expenditure for the meeting of medicinal treatment of such patients would be approximately Rs.40 lakhs per head. The aforesaid order was subjected to challenge by the Union of India before the

Supreme Court by filing Special Leave Petition Nos. 9870/2020 to 9873/2020. However, the said Special Leave Petitions were dismissed by the Supreme Court vide order dated 22.9.2020.

13. The Karnataka High Court also passed a similar order for treatment of such patients in **Writ Petition No.19061/2015-Lysosomal Storage Disorders Society in India Vs. State of Karnataka** on 24.2.2020, holding that it was duty of the Central Government and the State Government to ensure that justice is done to such patients and they will not allow any such contingency to happen. The Karnataka High Court vide order dated 24.2.2020 issued following interim directions:-

“(i) We direct the State Government to pay a total amount of Rs.595.1 Lakhs to the third respondent for a four-month block period from 1<sup>st</sup> March , 2020 to 30<sup>th</sup> June, 2020.

(ii) One fourth of the said amount of 595.1 lakhs shall be released by the State Government to the third respondent on or before 5<sup>th</sup> March, 2020 and thereafter, the remaining amount shall be deposited by the State Government with the third respondent in the same manner, that is, by depositing one fourth amount on or before 5<sup>th</sup> April, 2020, 5<sup>th</sup> May, 2020 and 5<sup>th</sup> June, 2020 respectively.

(iii) Needless to add that the amount which will be received from the State Government shall be spent by the third respondent for providing the treatment to 25 children. The amount pertaining to the two additional children shall be kept by the third in a separate account so that it can be utilized in case any such children are added to the list of 45 children.

(iv) It will be open for the State Government to make a representation to the Central Government (fourth respondent) to release a substantial contribution for making the payment to the third respondent. In the said representation, the State government shall, in the alternative, apply for grant of permission to appropriate the balance amount received for the financial year 2018-19 for making the grant to the third respondent. The State Government shall make such a representation immediately which will be decided by the Central Government within a period of three months from the date of making such a representation. We hope and trust that apart from the fundamental rights available to the children affected by rare diseases, the support will be extended by the Central Government.

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(v) The application for amendment is allowed. These petitions shall be listed under the caption of 'Order' on 1<sup>st</sup> April, 2020 when the notices issued to the newly added respondents will be made returnable.

(vi) The State Government shall file an affidavit of compliance by 31<sup>st</sup> March, 2020, a copy of which shall be served to all the concerned parties.

(vii) In the event the amount as directed under this order is not released on time by the State Government, it will be open for the third respondent to move this Court for seeking appropriate directions.”

14. Reference may also be made to the order passed by the High Court of Uttarakhand in *WPMS No.2312/2019 – Sumit Singh Vs. Union of India & others* dated 17.4.2020. In this case also, the patient was suffering from the same disease i.e. “Gaucher” with which the son of the petitioner herein is suffering. He was also required to undergo an Enzyme Replacement Therapy after every 14 days. The High Court of Uttarakhand took note of the fact that earlier policy of the Government of India provided that such expenses shall be borne by the Central Government and the State Government in ratio of 60:40. Therefore, that Court vide order dated 15.10.2019 directed for bearing the cost of treatment in that proportion by both the two Governments. The said order was extended vide subsequent order dated 8.1.2020 and thereafter, again it was extended by the aforesaid order dated 17.4.2020.

15. Reference may also be made to the order passed by the Kerala High Court dated 27.2.2020 in **W.A.No.2151/2017** and **W.P.(C) No.28250/2017 (s)- Lysosomal Storage Disorders Support Society Vs. State of Kerala & others**, whereby the Union of India was directed to pay a sum of Rs.1,50,00,000/- to the State corpus for the

treatment of rare diseases, such as Pompe, Gaucher, MPS-1 (Hurler Syndrome), fabry, RLER Syndrome and MPS-2 (Hurler Syndrome).

16. The right to health forms an integral component of the right to life enshrined under Article 21 of the Constitution of India. Reference in this connection may be made to two important judgments of the Supreme Court namely:- *Pt. Parmanand Katara Vs. Union of India* (1989) 4 SCC 286 and *Paschim Banga Khet Mazdoor Samiti Vs. State of West Bengal* (1996) 4 SCC 37. Article 25 of the Universal Declaration of Human Rights, ratified by India, which is considered as having the force of customary international law, declares as under:-

#### **Article 25**

(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

(2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

17. Similarly, Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which also has been ratified by India, details out the different facets of the right to health, which reads as under:-

#### **Article 12**

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

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- (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
- (b) The improvement of all aspects of environmental and industrial hygiene;
- (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
- (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

18. Article 24 of the Child Rights Convention (CRC), which has also been ratified by India, delineates the rights of the newly born and the young child as under:-

**Article 24:-**

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.
2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:
  - (a) To diminish infant and child mortality;
  - (b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
  - (c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
  - (d) To ensure appropriate pre-natal and post-natal health care for mothers;
  - (e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;

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(f) To develop preventive health care, guidance for parents and family planning, education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

19. The Protection of Human Rights Act, 1993 recognizes all the above conventions as part of human rights laws, therefore international human rights norms, as contained in the Conventions which have been ratified by India, are binding on India to the extent they are not inconsistent with the domestic law norms. Section 2(d) of the Act of 1993 (supra) defines “human rights” to mean “the rights relating to life, liberty, equality and dignity of the individual guaranteed by the Constitution or embodied in the International Covenants and enforceable by courts in India”.

In view of above, it must be held that right to health and medical care is one of the facets enshrined under Article 21 of the Constitution of India.

20. The Supreme Court in the case of *Union of India Vs. Moolchand Kharaiti Ram Trust* (2018) 8 SCC 321 held as under:-

“65. The State has to ensure the basic necessities like food, nutrition, medical assistance, hygiene etc. and contribute to the improvement of health. Right to life includes right to health as observed In *State of Punjab v. Mohinder Singh Chawla* (1997) 2 SCC 83. Right to life and personal liberty under Article 21 of the Constitution also includes right of patients to be treated with dignity as observed by this Court in *Balram Prasad v. Kunal Saha* (2014) 1 SCC 384. Right to health i.e.right to live in a clean,

hygienic and safe environment is a right under Article 21 of the Constitution as observed in *Occupational Health and Safety Association v. Union of India* (2014) 3 SCC 547=AIR 2014 SC 1469. The concept of emergency medical aid has been discussed by this Court in *Pt. Parmanand Katara v. Union of India* (1989) 4 SCC 286. In *Paschim Banga Khet Mazdoor Samity and others v. State of W.B.* (1996) 4 SCC 37, right to medical treatment has been extended to prisoners also.”

“67. In *Paschim Banga Khet Mazdoor Samiti (supra)*, this Court has observed that the Constitution envisages the establishment of a welfare State. In a welfare State, the primary duty of the Government is to secure the welfare of the people. Providing adequate medical facilities for the people is an essential part of the obligations undertaken by the Government in a welfare State. The Government discharges this obligation by running hospitals and health centres which provide medical care to the person seeking to avail of those facilities. Preservation of human life is thus of paramount importance. Government is duty-bound to provide timely care to persons in serious conditions. Medical facilities cannot be denied by the Government on the ground of non-availability of bed. Denial of medical assistance on unjust ground was held to be in violation of right to life under Article 21 and the State was directed to pay the compensation of Rs.25,000/- to the petitioner and requisite directions were issued by the Court. The State cannot avoid its constitutional obligation in that regard on account of financial constraints and was directed to allocate funds for providing adequate medical infrastructure.”

21. The Constitution Bench of the Supreme Court in *Navtej Singh Johar and others Vs. Union of India* (2018) 10 SCC 1, upon survey of previous case law held that right to health and health care is one of the facets of right to life under Article 21 of the Constitution of India. It was held that “the right to life is meaningless unless accompanied by the guarantee of certain concomitant rights including, but not limited to, the right of health. The right of health is understood to be indispensable to a life of dignity and well-being, and includes, for instance, the right of emergency medical care and the right to the maintenance and improvement of public health”. (See para 483 of the report).

22. Undeniably, the Central Government did promulgate the laudable policy for providing assistance to patients suffering from such rare diseases as the cost of such treatment is quite huge, exorbitant and prohibitive but later held it in abeyance. Relevant clause of the said policy, which provided for treatment of such patients with the support of Central Government as well as State Government in the ratio of 60:40, reads as under:-

**“4.3.1 Ministry of Health and Family Welfare**

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**o) Creating a National and State Level Corpus**

1. The Government of India (GOI) to set up a corpus fund with an initial amount of Rs.100 crore towards funding treatment of rare genetic diseases. Resources allocated for treatment of rare diseases can be progressively scaled up with regular improvements in availability of epidemiological data, cost estimation studies and measures taken to encourage development of drugs and for reduction in prices of drugs.
2. The States to have a similar corpus at the state level and the GOI will contribute funds towards the State corpus to the ratio of 60:40. It would be open to the States to contribute a larger amount to the corpus. This funding arrangement will be part of the PIP process.
3. The corpus fund will be dedicated for rare disorders. However, it will not fund treatment for blood disorders (hemophilia, thalassemia and sickle cell anemia) as separate government programs for them exist already. Depending on need, the existing programmes for blood disorders shall be scaled up.
4. The corpus will be used for only part funding of the entire treatment cost.
5. To ensure sustainability of the corpus, the Public Sector undertakings (PSUs) and corporate houses, to be encouraged to make contributions as per Section 135 and Schedule VII of the Companies Act as well as the provisions of the Companies (Corporate Social Responsibility Policy) Rules, 2014 (CSR Rules).

**(p) Creating a web-based application for online application process**

To ensure timely decisions and release of funds, a web-based application would be developed for creating online mechanism for



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applying to the corpus. Central Government will create this web-based application within 6-12 months of the release of this policy. It will have the details of the corpus and instructions and mechanism for applying for funding. It would be open to individuals institutions as well as State Governments to apply for funds by entering details on the web application as per instructions provided.”

**23.** It is not in dispute that the son of the writ-petitioner is suffering from life threatening disease “Gaucher” for which he has to necessarily undergo Enzyme Replacement Therapy after every 14 days to save his life. If timely treatment is not provided to him, there may be risk of his life. No doubt, respondent-writ petitioner does not fall in the category of below poverty line. Even if he belongs to a middle class family and is a practicing architect, he is a man of reasonable means. Moreover, he also has a family of four members to support, apart from his 4 year old son who is suffering from such rare disease. Left to himself, he shall have to arrange approximately Rs.50 lakhs per annum for his treatment. “Right to health” is one of the facets of the right to life under Article 21 of the Constitution of India. Therefore, it is the duty of the Central Government and the State Government to protect the life of citizen especially the children of tender age suffering from such rare disease.

**24.** In our considered opinion, the learned Single Bench was not justified in diluting its earlier order dated 22.6.2020 vide subsequent order dated 15.12.2020, requiring the State Government to pay entire amount for treatment of such disease with liberty to the State Government to recover the amount in that proportion from the Central Government. In our view, the direction given in the order dated 22.6.2020 for apportionment of the cost of treatment in that ratio of

60:40 between the Central Government and State Government was more appropriate. In the facts of the case, we are inclined to set aside the order dated 15.12.2020 and direct the Central Government to deposit Rs.27,00,000/- i.e. 60% of cost of treatment i.e. approximately Rs.45,00,000/- per annum with the State Government within a period of six weeks. However, the State Government shall pay the amount of the entire expenses of the treatment of the petitioner's son, without waiting for the said deposit by the Central Government and shall immediately release the amount for treatment of petitioner's son. This arrangement shall continue till finalization of the new policy by the Central Government.

**25.** The Central Government is directed to positively finalize the new policy by 31<sup>st</sup> March, 2021, as per its stand before this Court.

The appeal is accordingly allowed in part with no direction as to costs.

**(Mohammad Rafiq)**  
**Chief Justice**

**(Vijay Kumar Shukla)**  
**Judge**

C.