

ITEM NO.10

COURT NO.2  
(HEARING THROUGH VIDEO CONFERENCING)

SECTION IV-A

S U P R E M E C O U R T O F I N D I A  
R E C O R D O F P R O C E E D I N G S

Petition for Special Leave to Appeal (C) Nos.12063-12064/2021

(Arising out of impugned final judgment and order dated 23-04-2021 in WP No. 19061/2015 &amp; in WP No. 401/2018 passed by the High Court of Karnataka at Bengaluru)

UNION OF INDIA

Petitioner(s)

VERSUS

LYSOSOMAL STORAGE DISORDERS  
SUPPORTS SOCIETY OF INDIA & ORS.

Respondent(s)

(FOR ADMISSION; IA No.93491/2021 - FOR EXEMPTION FROM FILING C/C OF THE IMPUGNED JUDGMENT)

Date : 27-08-2021 These petitions were called on for hearing today.

CORAM :

HON'BLE MR. JUSTICE UDAY UMESH LALIT  
HON'BLE MR. JUSTICE AJAY RASTOGIFor Petitioner(s) Mr. Aman Lelhi, ASG  
Mr. Anmol Chandan, Adv.  
Ms. Swarupma Chaturvedi, Adv.  
Mr. Shantanu Sharma, Adv.  
Mr. Gurmeet Singh Makker, AORFor Respondent(s) Mr. Vikas Singh Jangra, AOR  
Ms. Vaishali Mittal, Adv.  
Mr. Siddhant Chamola, Adv.UPON hearing the counsel the Court made the following  
O R D E R

Mr. Aman Lekhi, learned Additional Solicitor General appearing for the petitioner invited our attention to Office Memorandum dated 01.02.2019 in terms of which "maximum financial assistance admissible under the Scheme" was to be Rs.15,00,000/- (Rupees Fifteen Lakhs Only).

The National Policy for Rare Diseases, 2021 which has been placed on record states in paragraph 10 as under:

**"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 I). 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.
  
- 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 healthcare 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."

It is, therefore, submitted that interim directions passed by the High Court were beyond the scope of the Policy, especially when the validity of the Policy was not specifically under challenge.

Mr. Vikas Singh Jangra and Ms. Vaishali Mittal, learned Advocates appearing for respondent no.1 on caveat submit that the amount of Rs.2 Crores has already been deposited by the State Government and the money has been disbursed for treatment of the concerned patients.

In the circumstances, we issue notice, returnable on 13.09.2021.

The petitioner is directed to deposit a sum of Rs.3 Crores in the Registry of the High Court before the next date of hearing. However, the money shall not be disbursed to Indira Gandhi Institute till further orders.

The respondents are at liberty to file their response within a week.

Rejoinder, if any, be filed within five days thereafter.

The matter shall be listed for disposal on 13.09.2021.

(MUKESH NASA)  
COURT MASTER

(VIRENDER SINGH)  
BRANCH OFFICER