

ITEM NO.23

COURT NO.1

SECTION X

S U P R E M E C O U R T O F I N D I A
RECORD OF PROCEEDINGS

WRIT PETITION (CIVIL) Diary No(s) .29711/2021

P. SREENIVASA CHAKRAVARTHY

Petitioner(s)

VERSUS

UNION OF INDIA & ANR.

Respondent(s)

**(FOR ADMISSION and IA No.159284/2022-CONDONATION OF DELAY IN
 REFILING / CURING THE DEFECTS)**

Date : 05-12-2022 This petition was called on for hearing today.

CORAM :

**HON'BLE THE CHIEF JUSTICE
 HON'BLE MR. JUSTICE PAMIDIGHANTAM SRI NARASIMHA**

For Petitioner(s) Mr. S.P. Singh, Sr. Adv.
 Mr. Rakesh Khanna, Sr. Adv.
 Mr. Gopal Verma, AOR
 Mr. Umang Verma, Adv
 Mr. Ganganmeet Singh Sachdeva, Adv.
 Ms. Ramya Khanna, Adv.

For Respondent(s)

**UPON hearing the counsel the Court made the following
 O R D E R**

- 1 Delay condoned.
- 2 The petitioner who has invoked the jurisdiction of this Court under Article 32 of the Constitution claims to be suffering from a condition called Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. The petitioner states that the condition is recognized by the World Health Organization as a neurological disease since 1969.
- 3 The grievance of the petitioner is that though a National Policy for Treatment of Rare Diseases was framed in 2017 and later revised in March 2021, no steps

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 Sanjay Kumar
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have been taken for diagnosing the treatment of the rare disease from which the petitioner suffers. It has also been stated that the Ministry of Health and Family Welfare of the Union of India launched a digital portal for crowd funding and voluntary donations for the treatment of patients with rare diseases.

4 In this backdrop, the petitioner seeks diverse reliefs which are extracted below:

- “(a) to direct the stake holders for recommendations on effective mechanism for diagnoses, assessment, treatment and research of patients suffering from Myalgic Encephalomyelitis/chronic fatigue syndrome and other Rare Diseases in India as being part of patient's fundamental rights enshrined in our Constitution of India vide Article 14, 21, 39, 41 and 47, and/or;
- (b) to issue writ in the nature of mandamus or any other appropriate order or direction thereby directing Respondents to open up the Centre of Excellence (treating hospitals) in all the 28 states and 8 union territories so that it is approachable for every rare disease patient in India, and/or;
- (c) to frame guidelines enforceable in law until suitable legislation is enacted by the State Legislatures/Parliament of India to occupy the field, and/or;
- (d) to issue writ in the nature of mandamus or any other appropriate writ order or directions directing the Respondents to devise a mechanism to make a wide publicity of rare diseases and to educate the various stake holders so as to find a mechanism of permanent cure for patients suffering from Myalgic Encephalomyelitis/chronic fatigue syndrome and other Rare Diseases in India as has been suggested by the Jawaharlal Institute of Postgraduate Medical Education & Research, Puducherry to the Petitioner, and/or;
- (e) to issue writ in the nature of mandamus or any other appropriate order or direction thereby directing Respondents to reconsider the National Policy for Rare Disease, 2021 in terms of the decision of this Hon'ble Court in Paschim Bangal Khet Mazdoor Samity v. State of W.B 1996 SCC (4) 37, Para 16 and set up adequate criteria and increase the budget limit so that treatment of all Rare Disease patients in India can be done effectively, and/or;

- (f) to issue appropriate directions to the Respondents so as to declare all the rare diseases declared by the World Health Organization as rare diseases in our National as well;
- (g) to issue writ in the nature of mandamus or any other appropriate order or direction thereby suggesting Respondents to come up with a comprehensive reimbursement/funding models like the Orphan Disease Act, 1983 of United States to provide economic incentives in form of tax credits, research grants and fee waivers as these financial incentives can be instrumental to encourage pharmaceutical companies to engage in manufacturing orphan drugs in India, and/or;"

5 Many of the reliefs which the petitioner seeks would require an expert scientific determination and policy decision at the appropriate level on what steps should be taken to ameliorate the condition of persons suffering from the condition. We are of the considered view that it would be appropriate if the grievance of the petitioner is examined by the Ministry of Health and Family Welfare of the Union Government so that after due consideration by experts, a considered decision bearing on a matter of policy and scientific expertise can be arrived at. The petitioner would be at liberty to prepare a comprehensive representation and submit it to the Secretary in the Ministry of Health and Family Welfare, together with a copy of this order, so that the matter can be examined expeditiously at the appropriate level.

6 The petition is accordingly disposed of.

7 Pending application, if any, stands disposed of.

**(SANJAY KUMAR-I)
DEPUTY REGISTRAR**

**(SAROJ KUMARI GAUR)
ASSISTANT REGISTRAR**