

(2022) 11 OHC CK 0208

In the Orissa High Court

Case No : Writ Petition (C) Nos. 14289, 25501 Of 2022

Anshuman Ray

APPELLANT

Vs

Union Of India And Others

RESPONDENT

Date of Decision : 24-11-2022

Acts Referred:

Citation : (2022) 11 OHC CK 0208

Hon'ble Judges : Dr. S. Muralidhar, CJ; M.S. Raman, J

Bench : Division Bench

Advocate : D.P. Dhal, G.M. Rath, P.K. Parhi, Babita Sahu

Judgement

1. An affidavit has been filed by the Under Secretary to Government of India, Ministry of Health and Family welfare on 9th November, 2022 where inter alia it is sought to be suggested that the patients suffering from rare diseases like Duchenne Muscular Dystrophy (DMD) have to approach the nearest 'Center of Excellence' (CoE) from where they can expect to get treatment. It is stated that as far as AIIMS, Bhubaneswar is concerned, it is not a CoE but wherever it makes a recommendation for a patient visiting it to get treatment with the nearest available CoE under the extant policy, the Union of India can provide financial assistance upto a maximum of Rs.50 lakh per patient. In para 30 of the affidavit, it is mentioned that AIIMS, New Delhi had submitted a proposal for 22 persons suffering from rare diseases and that the Government of India in accordance with the policy had released around Rs.11 crores to AIIMS, New Delhi. It is further stated that "similarly, all the cases where the CoE had requested for requisition, the answering Respondent is in the process of releasing the financial assistance of maximum upto Rs. 50 lakhs per patient for their treatment to the respective CoEs where such patients of rare diseases are being treated."

2. Mr. Parhi, learned Deputy Solicitor General on instructions states that while AIIMS, Bhubaneswar is not in a position to provide the treatment and particularly since the treatment requested i.e. AON is under clinical trial in India and not

approved yet by the DCGI, each of the 16 children, who have been referred to it by this Court are being advised to go to the other AIIMS elsewhere which have been declared as CoEs.

3. When the Court posed a question to Mr. Parhi, learned Deputy Solicitor General of India (DSGI) whether written instructions have been issued in respect of each of 16 children, he undertook to arrange for written advice to be issued in respect of each of the 16 children them to enable them to not only receive financial assistance as indicated in the above affidavit but treatment at the respective CoEs to which they will be referred.

4. For the above purpose, the 16 children will again be given specific dates on which they can visit AIIMS, Bhubaneswar to get the requisite treatment and written advice.

5. This exercise be completed within the next 10 days. Affidavit of compliance enclosing copies of the written advice provided to each of the children be enclosed with such affidavit.

6. List on 19th December, 2022.

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