

(2022) 09 OHC CK 0121

In the Orissa High Court

Case No : Writ Petition (C) PIL No. 14289 Of 2022

Anshuman Ray

APPELLANT

Vs

Union Of India And Others

RESPONDENT

Date of Decision : 16-09-2022

Acts Referred:

Citation : (2022) 09 OHC CK 0121

Hon'ble Judges : Dr. S. Muralidhar, CJ;Chittaranjan Dash, J

Bench : Division Bench

Advocate : D.P. Dhal, P.K. Parhi, Babita Sahu, Ishwar Mohanty

Judgement

1. This is a petition seeking directions to the Government of India as well as the State of Orissa to provide Antisense Oligonucleotide (AON) therapy free of cost to fifteen children at various locations in Odisha suffering from Duchenne Muscular Dystrophy (DMD).

2. This petition was first listed on 21st June, 2022 when time was sought by the learned Additional Government Advocate for the State of Odisha for instructions. On the next hearing, i.e., on 11th July 2022, the Court was informed that the High Court of Delhi had in W.P.(C) No.9684 of 2021 (Adhyan Jaiswal v. Union of India) passed orders on 14th December, 2021 and 1st February, 2022 issuing directions to the Union of India (UoI) to provide such free treatment to the children suffering from DMD. Similar orders had also been passed by the Calcutta High Court in CPAN No.564 of 2021 in WPA No.4016 of 2020.

3. The Court has been informed that the aforementioned order of the Delhi High Court was challenged by the Union of India by way of SLP (C) Nos.10152-10174 of 2022 in the Supreme Court of India. On 11th July, 2022 while disposing of the SLPs, the Supreme Court of India declined to entertain the SLPs while granting liberty to the UoI to advance its submissions before the Single Judge of the Delhi High Court before whom the writ petitions were still pending.

4. Mr. D.P. Dhal, learned Senior Advocate appearing for the Petitioners urges that

directions to the Union of India similar to the ones issued by the Delhi High Court in its order dated 1st February 2022, should be issued in the present case as well.

5. Mr. P.K. Parhi, learned Assistant Solicitor General of India (ASGI) representing both the Union of India, Department of Health and Family Welfare and AIIMS, Bhubaneswar (Opposite Party No.5) refers to the counter affidavit of AIIMS, Bhubaneswar to urge that the AON treatment involves very high cost and life-long therapy and, therefore, the National Policy for Rare Diseases, 2021 will have to be applied and the resources to provide such treatment would have to be found as envisaged therein. Reference is made to a Digital portal for crowd funding and voluntary donations for patients of Rare Diseases which is stated to have been made functional.

6. Mr. Parhi, learned ASGI adds that while AIIMS, Bhubaneswar will not hesitate to provide the treatment, the cost of treatment incurred will have to be reimbursed

7. As far as the above submission is concerned, the Court notes that a similar submission was made before the Delhi High Court and negatived by it in its order dated 1st February, 2022 where in Para-9, it was observed as under:

"9. On the last submission of Mr. Luthra, Mr. Oberoi would submit that AIIMS is not in a position to utilise the annual budget sanctioned to the AIIMS, for the treatment of petitioners herein. He also states that insofar as the petitioners who are suffering from Non-DMD disease, they can be directed to report to the Chairman of Rare Diseases, Dr. Madhulika Kabra day after tomorrow, on which date they shall be attended to and the treatment shall be started. I must state here that the submissions made by Mr. Oberoi are not at all appealing. The order passed on December 14, 2021 is very clear that the treatment of the petitioners i.e., children must start immediately. It is surprising that even after a period of one month no treatment has yet started. Insofar as funds are concerned, the Court in the said order has clearly stated that it is the responsibility of the Union of India to ensure necessary funds are provided to all Centres of Excellence including AIIMS as and when demanded for treatment of these children."

8. It is the above order that was challenged before the Supreme Court of India and was not interfered with.

9. Consequently, a direction is hereby issued to AIIMS, Bhubaneswar to provide treatment to the fifteen children whose names are set out in the writ petition and the cost of such treatment shall be reimbursed by the Government of India in the Department of Health and Family Welfare.

10. A direction is issued to the Director, AIIMS, Bhubaneswar to draw up a schedule for consultation of the said 15 children suffering from DMD with the Specialists in AIIMS, Bhubaneswar for the purpose of receiving the AON therapy in a time-bound manner. This be done in consultation with Mr. Parhi, learned ASGI as well as Mr. Dhal, learned Senior Advocate for the Petitioner. An affidavit

of compliance be placed before the Court on the next date.

11. List on 11th October 2022.

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