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* **IN THE HIGH COURT OF DELHI AT NEW DELHI**

\+ W.P.(C) 16566/2024

CENTER FOR ICHTHYOSIS RELATED MEMBERS FOUNDATION .....Petitioner

Through: Mr.Arvind, Advocate.

versus

UNION OF INDIA & ANR. .....Respondents

Through: Ms.Monika Arora, CGSC with Mr.Subhrodeep Saha, Advocate for R-1 & 2.
Ms.Mahamaya Chatterjee, GP with Ms.Antara Choudhury, Advocate.

CORAM:
HON'BLE THE CHIEF JUSTICE
HON'BLE MR. JUSTICE TUSHAR RAO GEDELA

O R D E R

% 02.12.2024

1. Present public interest petition has been filed seeking directions to the Respondents- Ministry of Social Justice & Empowerment and the Ministry of Health and Family Welfare to form a committee to oversee the patients suffering from Ichthyosis. The Petitioner further seeks direction to categorize the Ichthyosis disease as a disability under the Rights of Persons with Disabilities Act, 2016 ("RPWD Act").

2. Learned counsel for the Petitioner states that till date there is no permanent cure for the Ichthyosis disease and the people who are affected by it are discriminated by the public at large and undergo mental and physical agony.

3. He also states that most of the people suffering from the disease do not possess identity proofs because the disease makes them unfit to allow their biometric details to be captured.

4. He further states that the disease fulfills all the necessary conditions of Section 2(s) of the RPWD Act but owing to it not being categorized as a disability, persons suffering from it are exempted from the benefits that a disabled person gets under the RPWD Act. He also states that as per notification dated 23rd September, 2022, issued by the Ministry of Women and Child Development, ichthyosis has been classified as a skin disease which needs long term medication.

5. He also states that the Petitioner organization had filed a report dated 17th February, 2024 with the Respondent – Ministry of Health and Family Welfare and received a response dated 03rd May, 2024 wherein in twelve centers of excellence were identified and it was suggested to the Petitioner that any one of them can be approached for treatment. He states upon contacting the head of one of the centers, it was recommended *vide* email to the Petitioner to visit NIMS and get help in genetic testing. He submits that the said test is an expensive test and is difficult for severe Ichthyosis patients to afford.

6. He states that upon approaching a Dr.Pragnya Ranganath, the Petitioner was told that as per the government policy, Ichthyosis cannot be classified as a rare disease, as it doesn't have any treatment or cure. He further states that the Petitioner also received a response from a Dr.Rashmi Sarkar who stated that they were not aware about challenges Ichthyosis patients face in India.

7. After hearing learned counsel for the Petitioner and from a perusal of the paperbook, it is apparent that although the Petitioner has approached the Respondent-Ministry of Health & Family Welfare by submitting a report, but the prayers sought in the present petition have not been raised before the Respondents by submitting a prior representation. In the letter dated 17th February, 2024, the Petitioner has requested the Respondent-Ministry of Health and Family Welfare to include Ichthyosis as a rare disease under the National Policy for Rare Diseases 2021 and not as a disability under the RPWD Act.

8. Consequently, the present writ petition is disposed of with a direction to Respondent No.1 to treat the present writ petition as a representation and to decide the same in accordance with law, as expeditiously as possible, after giving an opportunity of hearing to the Petitioner and after taking input from the concerned experts/committees.

MANMOHAN, CJ

TUSHAR RAO GEDELA, J

DECEMBER 2, 2024
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