# Master Arnesh Shaw vs Union Of India & Anr on 28 January, 2021

## Author: Prathiba M. Singh

## Bench: Prathiba M. Singh

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*  IN THE HIGH COURT OF DELHI AT NEW DELHI
+  W.P.(C) 5315/2020 & CM APPL. 19189/2020
MASTER ARNESH SHAW ..... Pe
Through: Mr. Vivek Chib, Mr. Rahul
Mr. Asif Ahmed, Mr. Vikh
and Mr. Manas Tripathi,
(M:9899218215)
versus

UNION OF INDIA & ANR.
Through: Mr. Ripudaman Bha
with Mr. Kushagra
for R-1.
Mr. Satvik Varma
Oberoi, Advocates
With
+  W.P.(C) 322/2021 & CM APPL. 812/2021
KESHAV SHARMA AGE 12 YEARS THROUGH: HIS NEXT
FRIEND AND NATURAL FATHER SANJEEV
KUMAR .....
Through: Mr. Ashok Agarwal and Mr
Utkarsh, Advocates.
versus

UNION OF INDIA & ANR.
Through: Mr. Ajay Digpaul,
Kamal R. Digpaul,
Mr. V.S.R. Krishn
2/AIIMS.
CORAM:
JUSTICE PRATHIBA M. SINGH
ORDER

% 28.01.2021

1. This hearing has been done by video conferencing.

2. Both these matters concern two Petitioners who were suffering from a rare disease called Duchenne Muscular Dystrophy (hereinafter 'DMD'). On the last date this Court had observed that patients suffering from a rare disease ought not to be deprived of treatment owing just to the exorbitant price of the drug or treatment required for the said rare disease. The Court had considered the fact that the Right to Health and Healthcare falls within the ambit of the Right to Life, as recognised by the Supreme Court. As such, the Right to Health and Healthcare being a fundamental Right under Article 21 of the Constitution of India, it is imperative that the society in general, and the authorities in particular, ensures that such a right of a patient is safeguarded and not compromised, even with a small window of improving their chances of survival or bettering their quality of life. Considering the exorbitant price of the drug and the treatment, this Court had passed directions on the last date to the following effect:

> "7. As per the above draft policy, in view of the constraint of governmental resources, and competing health priorities, the government proposes that it cannot fully finance the treatment of all high cost rare diseases, but the gap can be filled by seeking donations from prospective individuals or corporate donors, who are willing to support the cost of such diseases. Thus, the government has recognised that DMD is a rare disease and has also recognized the fact that patients in general may not be able to afford its treatment. The Government thus proposes that it shall explore crowd funding as an option to address affordability concerns.
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> 8. This court is of the opinion that the finalisation of the Draft Health Policy for Rare Diseases cannot be kept pending indefinitely, especially when common human lives are at stake. The earlier Policy having been kept in abeyance, it is incumbent for the Government to finalise and notify the Policy at the earliest. Accordingly, it is directed as under:
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> (1) A specific timeline shall be provided by the Secretary, Ministry of Health and Family Welfare, in respect of the finalisation and notification of the Draft Health Policy for Rare Diseases, 2020. (2) Insofar as the Petitioners, who are suffering from DMD, are concerned, the Secretary - Ministry of Health and Family Welfare would proceed in terms of the draft policy and explore crowd funding, including through prospective individuals, corporate donors and independent foundations, which exist to fund such treatments.

The Ministry shall in addition also contact the company M/s Sarepta Therapeutics, USA, which publicly advertises that it provides financial support/ medication in deserving cases, as is evident from their website. The Ministry shall come up with a proposal, with respect to the same, within the next 10 days."

3. Pursuant to the above order, an affidavit dated 28th September, 2020, has been filed by the Under Secretary at the Ministry of Health and Family Welfare (hereinafter as 'MHFW'), New Delhi

confirming that the National Policy for Treatment of Rare Diseases (hereinafter 'National Policy'), which was earlier formulated in July, 2017, was kept in abeyance vide non- statutory Gazette Notification dated 18th December, 2018, till a revised version of the National Policy was issued. Thereafter, an Expert Committee was constituted by the MHFW in November, 2018 to review the said policy and to draft the revised National Policy. The Expert Committee is stated to have submitted a report which was titled as 'The Draft National Policy for Rare Disease, 2020' and the same was put up in public domain for comments from stakeholders. The affidavit then confirms that a national policy is likely to be finalised by 31 st March, 2021 and a digital platform is also being created which is also likely to be operational by 31st March, 2021.

4. Considering the fact that for the last more than three years, there has been no policy to deal with patients suffering from rare diseases, the MHFW is now directed to finalise and put in public domain, the National Policy on or before 31st July, 2021. Simultaneously, since the said policy also contemplated voluntary crowd funding for treatment, the creation of a digital platform is also essential to enable patients like the Petitioners to avail of funding for medicines and treatment. Considering the urgency in the matter, the digital platform is also directed to be made operational on or before 31st March, 2021.

5. Insofar as funding for the two patients who are the Petitioners before this Court are concerned, the affidavit filed by the MHFW states that an e- mail dated 19th January, 2021 has been written to M/s Sarepta Therapeutics, Sarepta Therapeutics Headquarters, 215 First Street, Cambridge, MA 02142, in compliance with the order of this Court dated 12th January, 2021. The concerned representative of the MHFW shall send a reminder to M/s Sarepta Therapeutics, and also contact them telephonically if possible, and place their response before the next date.

6. The concerned official of the MHFW shall also join the proceedings on the next date.

7. List on 4th February, 2021.

PRATHIBA M. SINGH, J.

JANUARY 28, 2021 Dj/Ap