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# Mohd. Ahmed (Minor) v. Union of India

## W.P. (C) 7279/2013; MANU/DE/0915/2014

### 17.04.2014, Delhi High Court

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PALLAVI LAKHERA<sup>1</sup> AND SUMANTA SARKAR<sup>2</sup>

#### ABSTRACT

*In spite of the steady increasing government contribution to healthcare, the issue of Rare Diseases was seriously neglected for an extended time. Subsidized drugs for cure of individuals affected by rare conditions were also rare. These subsidies are essential for citizens experiencing rare disorder, as majority of these patients are from economically backward strata.*

*Since a considerably long time a kind of struggle was ongoing ahead of Indian courtroom searching government's attention and fiscal involvement towards these 'Rare Diseases'. India is amongst the countries using the lowest public health financing on the planet, with public health care system in the country only getting 1.26 percent of the whole GDP.*

*The missing support in political figures, for example a complete lacuna of any sort of law on rare diseases was expressed for first time in 2016 when the Delhi High Court dictated Health Ministry to launch a 'National Rare Disease Policy'.*

*The present case in question marks the initiation of the battle before the court of law and the way the judges have responded to the government's plea of having 'minimal Resources as well as the equitable distribution of exactly the same'.*

**Keywords:** *Rare Diseases, Right to Health, Healthcare.*

## I. INTRODUCTION

The health industry plays an important role in the economy of any country, developing and developed nations alike. However, several states have ignored or failed that this issue of developing genetic disorders and thus, extensive research is still required to cancel them. In certain countries such as the united states, nearly 17 percent of their GDP has been spent on medical care. These statistics appear to be compliant with all epic American market, allowing states with similarly sized markets to devote equal levels on medical improvement. Like a developing country, India had a budget of Rs.1900 Crores in 2019-20 for clinical research,

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which appears strikingly disproportionate to the health needs in excess of 135 crore population. India is among the states having the lowest public health funding on the planet, with public healthcare system in the country merely getting 1.26 percent of their complete GDP. In 2017 the Indian government implemented a plan directed towards fixing the dire need of research in genetic diseases and help with patients suffering from such rare diseases.

Despite the steady increasing government support to medical research, this industry i.e. Rare Disease Research, was neglected for a protracted period of time. Subsidized drugs for treatment of patients affected by rare diseases were uncommon. All these subsidies are necessary for citizens suffering from rare disorder, as majority of such patients are from economically backward strata. The concentration of wealth in the hands of a few in India, has led in several citizens falling beneath a bracket of financial deprivation. This pattern further extends itself in to the rarity of these diseases and the intermittent nature of these own impact. Just like genetic diseases, it's scientifically impossible to earth hereditary anomalies to a specific way of life, thereby affecting a larger diaspora of the population.

'Rare' or 'Orphan' ailments have received scant consideration to the public domain ; even more so in the current scenario owing to the pandemic. Treatment for these ailments, exactly in which obtainable, are usually pricey and recurring, making it unaffordable for most. Budget for these infections is provided from the government through *Rashtriya Arogya Nidhi* (RAN). In the monsoon session of Parliament, a question on finance allocation and utilisation of the capital under RAN had been raised. Budgets assigned for the component(RAN) for 2018-19 and also 2019-20 were 7.5 crore and 25 crore Rupees respectively. However, zero resources were released in 2018-19 while Rupees 1.5 crore was released in 2019-20.

A major repeated issue is that, various nations have a tendency to forget is the issue of Rare illnesses. During the last century, even several countries like USA, Japan and Russia have diverted their resources and laws towards battling rare-diseases. India has just recently begun spending heed for this problem. The missing support in political figures, for example a complete lacuna of any sort of law on rare diseases was expressed for first time in 2016 when the Delhi High Court dictated Health Ministry to launch a 'National Rare Disease Policy'.

A second more puzzling concern is that utilisation is quite low too, despite high demand for funds. According to some numbers, around 200 children in India suffer from a set of rare diseases classified as Lysosomal Disorders (LSD), and have applied to the Health Ministry for assistance. Industry sources estimate that the average cost of treatment for a child weighing approximately 10 kg could vary from ₹18-45 lakh. Several rare diseases, including LSDs, are

generally chronic in nature with high and recurring treatment costs.

However, RAN only provides for a one-time grant of ₹15 lakh as treatment support at government hospitals for specified rare diseases. In the above example, the support given by RAN is insufficient to pay the cost of the least possible estimate of one-time remedy itself, let alone recurring expenses. Is the minimal allocation of funds that does not even meet minimal therapy costs a deterrent to utilisation?

Another reason for such low utilisation might be lack of knowledge of rare diseases and access to such funds.

It is clear that the people suffering from rare disorders are not getting adequate support. Consequently, the battle has already been started before the Indian Courts to recognise the issue of the 'Rare Diseases' and this battle started with a 2013 case of *Mohd Ahmed (Minor) vs. Union of India*, which is one of the landmark case on the issue and hence the subject matter of our discussion.

## II. FACTS OF THE CASE

**Martin Luther King Junior** said, "*of all forms of inequality, injustice in health care is the most shocking and inhumane*". The present case many years subsequent exemplifies what he had said.

The facts of the current case are that the petitioner is a young boy aged about seven years and is represented through his next friend, his dad, *Mr. Mohd. Sirajuddin*. The facts of the current case are that the petitioner is a young boy aged about seven decades and is represented during his next friend, his dad, *Mr. Mohd. Sirajuddin*. The petitioner suffers from a rare genetic disease named Gaucher Disease, which is a Lysosomal Storage Disorder, where the body can't process fat leading to accumulation of fat around vital organs of their human body. Petitioner is the only surviving child of his parents; his other 3 siblings have succumbed to the identical disease.

A remedy by the title of Enzyme Replacement Therapy is available with this particular disorder. It's anticipated that individuals receiving this therapy have a high level of normalcy. Petitioner's dad, who's a rickshaw puller by profession can't afford the same.

Presently the medication necessary to treat this illness are made by three pharmaceutical firms internationally, Sanofi, Shire and Pfizer. Of these, just 1 company, Sanofi sells its Gaucher's medication in India. The expense of this treatment is projected at roughly rupees six-seven lakhs each month. The main reason for the exorbitant price of this treatment is that Gaucher falls in the class of rare diseases. As small amount of individuals suffer with rare diseases,

pharmaceutical companies cannot recoup their research and development costs over a large base of individuals. It's because of this that these medications are costlier at a worldwide level. No Indian drug company has developed a competing medication for this disorder till date.

But, *'each cloud has a silver lining'*.

The petitioner has exhausted his initial remedy in August 2013 availing of monetary assistance in the *'Delhi Arogya Kosh'*, which offers financial aid to the degree of rupees five lakhs to destitute eligible patients. So, together with Delhi Government's fiscal assistant one month's therapy was provided to the plaintiff.

Additional since throughout the pendency of this current request, petitioner needed urgent medical care, on 29th January, 2014 *Medanta - The Medicity Hospital*, Gurgaon, Haryana provided a month's free therapy for enzyme replacement to this petitioner. Afterward, on the oral request of the Court, attorneys of Delhi High Court voluntarily led Rupees Seven Lakhs Seventy Five Thousand for petitioner's treatment. The aforesaid amount was transferred into the accounts of Director, AIIMS whereas the petitioner is presently undergoing a second month's therapy of enzyme replacement.

Not only-but too as soon as the judgment was going to be booked, the Amicus Curiae, *Ms. Shyel Trehan* passed within an E-mail dated 1st April, 2014 composed to *Medanta- The Medicity Hospital*, Gurgaon, Haryana from Mr. Anil Raina, Director - Industry (India & South Asia), Genzyme - A Sanofi Company offer to give treatment free of cost limited to a span of 3 months.

Furthermore, on 3rd April, 2014, *Mr. A.S. Chandiok*, Senior Advocate said that Delhi High Court attorneys have increased a further quantity of rupees four lakhs approx.

Ahead of commencement of arguments, this Court gave an chance to the Central and State Governments to find out whether the issue may be amicably solved. However, the meeting wasn't too profitable. Thus, on 25th March, 2014, this Court started hearing closing arguments.

### III. ISSUES BEFORE THE COURT

1. Whether a minor child born to parents belonging to economically weaker section of the society suffering from a chronic and rare disease, Gaucher, is entitled to free medical treatment costing about rupees six lakhs per month especially when the treatment is known, prognosis is good and there is every likelihood of petitioner leading a normal life.

2. Whether availability of finances is a relevant factor for a State to take a plea that it does not have enough resources to help patients suffering from the 'Rare Diseases'?

3. Whether the Supreme Court has diluted the 'Right to Health' through its earlier judgements?

#### IV. PETITIONER'S ARGUMENTS

**Mr. Ashok Aggarwal**, learned counsel for petitioner said that because treatment of petitioner's disease was accessible in India, both the AIIMS, Central Government and Government of NCT of Delhi, were bound under Article 21 of the Constitution of India to supply free remedy to this petitioner and for similar patients. He further highlighted that the 'Right to health' was signified in Article 21 of our Constitution.

To back his submissions, he relied upon a Division Bench's judgment of this Court in the case of *All India Lawyers Union (Delhi Unit) vs. Govt. of NCT of Delhi & Ors.*<sup>3</sup>

According to him, the principles were flexed or revised whenever powerful or influential people needed to be accommodated in the subject of supplying medical care in State expense.

Further, **Mr. Aggarwal** said that the Government of NCT of Delhi that was taking the excuse of fiscal restriction in providing treatment to the petitioner, had remunerated Rs.1.32 crore as medical cost into some MLA in Rohtas Nagar.

In addition, he submitted that while providing free treatment for Government workers at State cost and at precisely exactly the exact identical time denying free remedy into the non-Government workers (average person ) in the alleged ground of financial limitations was arbitrary, discriminatory and struck Articles 14 and 21 of the Constitution of India.

**Mr. Aggarwal** argued that the Central Government have to bring "Public Health" in Concurrent list of Constitution and make "Right to Public Health" a Fundamental Right. Additionally, the state has to enact a Central Legislation on Right to Public Health.

Lastly, he also pointed out that the Cuban Constitution adopted in 1976, obligated the State to assure that there shall be "no sick person who does not receive medical attention." He stated that the Central Government should forthwith frame a National Policy on Right to Public Health and till such Policy was framed, the petitioner and the like patients should be provided free treatment at State expense.

Finally, in addition, he pointed out that the Cuban Constitution adopted in 1976, bounded the State to ensure there will be "*no sick individual who doesn't receive medical care.*" He said that the Central Government must forthwith framework a National Policy on Right to Public Health

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<sup>3</sup> 163 (2009) DLT 319 (DB)

and until Policy was styled, the petitioner and the similar patients ought to be supplied free treatment in State expense.

## V. RESPONDENT'S ARGUMENTS

### (A) Arguments On Behalf Of Delhi Government

**Ms. Zubeda Begum**, the counsel for Govt. Of NCT of Delhi said that in comparison to other States of the nation, the Govt. Of NCT of Delhi had allocated ten per cent of its funding towards health and wellness which was highest in the country. She further stated that although Delhi having only one percent of the populace of the nation, it was spending four times on health, calculated on a pro rata basis, in comparison to other states of the country.

She also pointed out that Delhi had a comprehensive drug policy. She said that in 2013 the Essential Medicine List had been revised to the eighth time by an expert Committee comprising of eminent Doctors.

Ms. Zubeda Begum supplementarily pointed out that the following four Schemes which were being funded by the Government of NCT of Delhi:-

1. '*Delhi Arogya Kosh*'\_which provided financial assistance upto Rs.5 lakh to eligible patients. During the current FY 2013- 2014, an amount of approximately Rs.4.9 crores had been disbursed.
2. '*Delhi Arogya Nidhi*': This Scheme provided financial assistance upto Rs.1.5 lakh to eligible patients.
3. '*Delhi Kalyan Samiti*', and
4. *L.G./Chief Minister's Relief Fund*.

She said that for individual experiencing genetic disorders such as Lysosomal Storage Disorders (Gaucher's disease etc.. ) the medication for bypass Enzyme Replacement Therapy (ERT) wasn't insured even beneath the public healthcare program in the united states. She said that patients in the USA were financially supported by the health care and other philanthropic association like contributions from Corporates, Institutions, Charities, etc..

She further submitted that the right to health in a developing country like India could not be so stretched so as to mean to provide free health facilities to a terminally ill patient while other while other taxpayers weren't even given basic healthcare. She said that the State had the equivalent responsibility towards all taxpayers and it needed to use its own limited funds in order to supply the utmost benefit to the maximum number of individuals living in the country.

Furthermore, she proposed that the Supreme Court in subsequent judgments in *State of Punjab*

**& Ors. vs. Ram Lubhaya Bagga**<sup>4</sup>, and **Confederation of Ex-servicemen Associations and Ors. vs. Union of India & Ors.**<sup>5</sup>, had diluted the right to health.

In **State of Punjab & Ors. vs. Ram Lubhaya Bagga**<sup>6</sup>, the court has stated that “When we speak about a right, it correlates to a duty upon another, individual, employer, government or authority. In other words, the right of one is an obligation of another. Hence the right of a citizen to live under Article 21 casts obligation on the State. This obligation is further reinforced under Article 47, it is for the State to secure health to its citizen as its primary duty. However, “No State of any country can have unlimited resources to spend on any of its projects. That is why it only approves its projects to the extent it is feasible. The same holds good for providing medical facilities to its citizens including its employees. Provision of facilities cannot be unlimited. It has to be to the extent finances permit.”<sup>7</sup>

**Confederation of Ex-servicemen Associations and Ors. vs. Union of India & Ors.**<sup>8</sup>, the court stated that “In our considered opinion, though the right to medical aid is a fundamental right of all citizens including ex-servicemen guaranteed by Article 21 of the Constitution, framing of scheme for ex-servicemen and asking them to pay —one-time contribution neither violates Part III nor is it inconsistent with Part IV of the Constitution. Ex-servicemen who are getting pension have been asked to become members of ECHS by making —one-time contribution of reasonable amount (ranging from Rs 1800 to Rs 18,000). To us, this cannot be held illegal, unlawful, arbitrary or otherwise unreasonable.”<sup>9</sup>

In this regard, she also mentioned to the General Comment 14 issued by the UN Committee on Economic, Social and Cultural Rights in 2000. The applicable portion of the aforementioned Comment relied upon by her reads as under:-

“The notion of the ‘highest attainable standard of health’ in Article 12(1) of ICESCR takes into account both the individual's biological and socio-economic preconditions and a State's available resources. There is a number of aspects which cannot be addressed solely within the relationship between States and individuals; in particular, good health cannot be ensured by a State, nor can States provide protection against every possible cause of human ill health. Thus genetic factors, individual susceptibility to ill health and the adoption of unhealthy or risky lifestyles may play an important role with respect to an individual's health. Consequently,

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<sup>4</sup> (1998) 4 SCC 117

<sup>5</sup> AIR 2006 SC 2945

<sup>6</sup> supra

<sup>7</sup> Para 26 and 29, (1998) 4 SCC 117

<sup>8</sup> supra

<sup>9</sup> Para 66, AIR 2006 SC 2945

*the right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health.”*

Thus, it has recognized the obligation and the duty of the state in this regard but also recognized the limitations which a state might face while trying to achieve this ideal. It also provides that all the patients have to be treated equally.

Therefore, based on what has been said by *Ms. Zubeda Begum*, the State can't focus all of its resources on a single individual, while denying fundamental amenities to other people.

#### **(B) Union of India's Submissions**

Likewise, respondent No.1-UOI stated that it conceded financial assistance to poor patients under the *Rashtriya Arogya Nidhi Scheme*, the Health Minister's Discretionary Grant and the Prime Minister's Relief Fund.

#### **(C) Submissions On Behalf Of AIIMS**

Respondent No.3-AIIMS confirmed that the petitioner is suffering from Gaucher disease and that it was conducting a philanthropic program wherein sixteen patients were under treatment for Gaucher's disease. Of these, treatment of five patients is being sponsored by the guardian's employers and the remaining patients are part of a Gaucher's treatment program managed by two pharmaceutical companies Shire and Genzyme. AIIMS listed that it had no fund for treatment of any of these patients. In fact, it affirmed that it did not have ample budget to manage its daily operation, leave alone fund the petitioner's treatment.

#### **(D) Summary of Respondents' Submissions**

In summary the State Government, the Union of India and AIIMS stated that in view of their constrained resources they were unable to finance the treatment of the petitioner because it had been lifelong and his illness was chronic.

### **VI. SUBMISSIONS OF AMICUS CURIAE**

*Ms. Shyel Trehan*, erudite Amicus Curiae submitted that Courts have taken different views with respect to the issue of constraint of resources in providing health care at the expenditure of the State.

She has highlighted that in the case of *Paschim Bangal Khet Mazdoor Samity and Others Vs. State of W.B. and Another*<sup>10</sup>, while focusing the argument with regard to lack of resources put

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<sup>10</sup> (1996) 4 SCC 37

forth by the State, the Supreme Court had held that it was the constitutional commitment of the State to provide passable medical services to the people.

*Ms. Trehan* further stated that the Courts in the United Kingdom had also had the prospect to scrutinize this issue. In the case of **R.V. Cambridge Health Authority Ex pare B (A Minor)** [1995] EWCA Civ 49, where the treatment for a child distressed from *non-Hodgkins Lymphoma* had failed and treatment that was considered experimental was sought under the National Health Service of the UK, the Court denied to interfere while admitting the strain on resources and that the question of allocation of resources was a policy decision observed that, *“Difficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment which the Court can make”. The Court concluded that, “I have no doubt that in a perfect world any treatment which a patient, or a patient's family, sought would be provided if Doctors were willing to give it, no matter how much it cost, particularly when a life was potentially at stake. It would however, in my view, be shutting one's eyes to the real world if the Court were to proceed on the basis that we do live in such a world. It is common knowledge that health authorities of all kinds are constantly pressed to make ends meet.”*

She further affirmed that the healthcare sector was unacceptably under-served and the allocation and accessibility of various drugs, implants and devices was well short of the preferred level. It was therefore a urgency to attract CSR donations to the healthcare sector, both in cash and kind.

#### **(A) Suggestions On Behalf Of Mr. Anand Grover, Senior Advocate**

**Mr. Anand Grover**, learned senior counsel who takes operational interest in pharmaceutical matters has indicated that as India is a signatory and has ratified the International Covenant of Economical, Social and Cultural Rights (ICESCR), and hence it was duty bound to realize its international legal obligations under the said treaty.

He submitted that States are required to embrace and implement a public health strategy and plan of action that reflects the epidemiological burden of disease that not only speak to major disease burdens but also the health distresses of the whole population. Therefore, according to him, even if a small percentage of the population had a life-threatening condition there should be public health strategy and plan to address their treatment wants. In other words, the Government can be directed to have a plan in place to make medicines accessible for rare diseases, like Gaucher disease etc.

Mr. Grover also highlighted that the courts in Argentina have ordered the State to ensure an

continuous supply of antiretroviral drugs to persons with HIV/AIDS<sup>11</sup>, to ensure the manufacturing of a vaccine against an endemic disease<sup>12</sup>, and to guarantee the continued delivery free of charge of a drug against bone disease.<sup>13</sup>

## VII. COURT'S OBSERVATIONS AND REASONING

The Court in the present case revealed that the petitioner was affected by a condition that impacts such smallish quantities of people that medication for all these diseases/conditions are generally known as "*orphan drugs*".

A variety of nations have adopted different policies to provide affordable therapy for patients suffering from chronic and rare diseases/conditions.

In the **United States**, Orphan Drug Act, 1983 defines the expression 'rare disease or condition' to imply any disease or condition which occurs so infrequently that there's not any realistic expectation that the price of creating and making accessible a drug for such disease or condition will be recovered by earnings of this kind of medication. The Orphan Drug Act, 1983 not merely extends tax charge in addition to patent duration of these medications but the authorities gives grants and enters into contracts with entities to help in defraying the expenses of expenditures incurred in relation to the advancement of drugs.

The European Union Regulation 1999 provides incentive of market exclusivity to the patrons of orphan drugs. Further, through the EUROPLAN, the **European Union** has assigned that each member country should develop a National Strategy Plan for rare diseases embracing a seven step involvement, viz. policy making, definition and classification of rare diseases, research on rare disease, creation of centres of expertise for rare diseases, gathering proficiency at EU level, empowering patient organizations and sustainability of the strategies.

Several other countries such as Japan, Australia and Israel have developed policies to combat the complications of rare diseases and orphan drugs.

Sad to say, the **Government of India** doesn't have any policy measure set up to deal with uncommon diseases, especially those of a chronic nature. Each of the Central and State approaches in the highest supply for a one- time award for life threatening procedures and don't consider continuous financial aid for a chronic illness like gaucher, which entails lifelong

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<sup>11</sup> Supreme Court of Justice, Asociacion Benghalensis y otros vs. Ministerio de Salud y Accion Social, case 323:1339, 1 June 2000

<sup>12</sup> Federal Administrative Court, Chamber IV, Viceconte, Mariela v. Estado nacional - Ministerio de Salud y Accion Social slamparo ley 16.986, 2 June 1998

<sup>13</sup> Supreme Court of Justice, Campodonico de Beviacqua, Ana Carina v. Ministerio de Salud y Accion Social - Secretaria de Programas de Salud y Banco de Drogas Neoplasicas, 24 October 2000

investment. There are no incentives in place for Indian producers to come up with local options to orphan drugs.

Consequently, the Court in the specified case was of the opinion that neither any promising orphan drug is going to be manufactured nor the prohibitive price tag of 'orphan drugs' may observe a decrease unless amendments are made in the relevant laws to lower the costs of developing such drugs and also to give financial incentives to create such medications such as discussed in the abovementioned nations. However, keeping in view the notion of separation of powers as incorporated in the Constitution, this Court cannot direct Parliament to enact a Central legislation on Right to Public Health or concerning rare diseases or orphan drugs, even though the same may be exceptionally looked-for. Similarly, as formulation of a policy is within the exclusive sphere of the Executive, this Court abstains from issuing directions.

Consequently, the issue raised in the present proceedings is to be decided in the context whether the Indian Government owes a constitutional duty to provide free medical treatment to the petitioner suffering from a rare and a chronic disease, even though the treatment is expensive and recurring.

This Court is of the view that whilst the jurisprudence of different countries discussed above on the subject of healthcare access contains valuable insights, it is important to bear in mind that our Constitution is structured differently from the aforesaid Constitutions.

In fact, though the issue raised in the present proceedings is common to all developing countries, yet India is fortunate to have a developed, liberal and progressive Constitution. As held by Justice Chaskalson P. of South African Constitutional Court in *T. Soobramoney vs. Minister of Health (Kwazulu-Natal)*<sup>14</sup> the Indian Supreme Court has developed a jurisprudence around the right to life so as to impose positive obligations on the government in respect of the basic needs of its inhabitants.

### **Right to Health is a Facet of Article 21**

The Indian Supreme Court in a catena of cases has held that right to health and medical care is a fundamental right under Article 21 read with Articles 39(e), 41 and 43. It has further held that self-preservation of one's life is the necessary concomitant of the right to life enshrined in Article 21, fundamental in nature, sacred, precious and inviolable.

In fact, in *State of Maharashtra Vs. Chandrabhan*<sup>15</sup>, the Supreme Court held that right to life, enshrined in Article 21 means something more than survival or animal existence. It includes

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<sup>14</sup> Case CCT 32/97

<sup>15</sup> AIR 1983 SC 803

all those aspects of life which go to make a man's life meaningful, complete and worth living. That which alone can make it possible to live must be declared to be an integral component of the right to life.

The human right to health is also recognized in numerous international instruments. Article 25.1 of the Universal Declaration of Human Rights affirms: "*Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services*".

The International Covenant on Economic, Social and Cultural Rights provides the most comprehensive article on the right to health in international human rights law. In accordance with article 12.1 of the Covenant, States parties recognize "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health", while article 12.2 enumerates, by way of illustration, a number of steps to be taken by the States parties to achieve the full realization of this right.

The General Comment No. 14 and the General Comment No. 3, issued by the United Nations Committee on Economic, Social and Cultural Rights in 2000 states were also discussed in the case which talks about the essential elements and the obligations, the precise application of which is required to implement and the realization of the right to health in all its forms.

Several regional human rights instruments also recognize the right to health, such as the European Social Charter of 1961 as revised (art. 11), the African Charter on Human and Peoples' Rights of 1981 (art. 16) and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights of 1988 (art. 10). Similarly, the right to health has been proclaimed by the Commission on Human Rights, as well as in the Vienna Declaration and Programme of Action of 1993 and other international instruments.<sup>16</sup>

This Court was of the view that Article 21 has to be interpreted in conformity with International Covenant on Civil and Political Rights, 1966 as India is a signatory to the same.

The Indian Supreme Court in the case of *Pt. Parmanand Katara Vs. Union of India and Others*<sup>17</sup>, recognized the obligation of the Government to preserve life. In the said case a victim of a scooter accident was denied treatment as the hospital did not have the requisite arrangements for medico-legal cases. Failure to receive timely treatment eventually led to the victim's death. While interpreting the ambit of the right to life under Article 21 of the

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<sup>16</sup> United Nations. Economic and Social Council. The Right to the highest attainable standard of health : 08/11/2000. E/C 12/2000/4

<sup>17</sup> (1989) 4 SCC 286

Constitution, the Supreme Court held “Article 21 of the Constitution casts the obligation on the State to preserve life. ....The obligation being total, absolute and paramount, laws of procedure whether in statutes or otherwise which would interfere with the discharge of this obligation cannot be sustained and must, therefore, give way.”

In the case of **Paschim Bangal Khet Mazdoor Samity and Others**<sup>18</sup>, a member of the petitioner Mazdoor Samity suffered a brain injury after falling from a train and was denied treatment at several hospitals due to lack of expertise and lack of beds and was forced to seek treatment at a private hospital. The petition was filed for compensation of the expenses incurred. The Supreme Court observed that the obligation to provide medical care was an obligation of the welfare state and held “The Constitution envisages the establishment of a welfare State at the federal level as well as at the State level. In a welfare State the primary duty of the Government is to secure the welfare of the people. The government hospitals run by the State and the medical officers employed therein are duty-bound to extend medical assistance for preserving human life. Failure on the part of a government hospital to provide timely medical treatment to a person in need of such treatment results in violation of his right to life guaranteed under Article 21. ....It is no doubt true that financial resources are needed for providing these facilities. But at the same time it cannot be ignored that it is the constitutional obligation of the State to provide adequate medical services to the people. Whatever is necessary for this purpose has to be done.....In the matter of allocation of funds for medical services the said constitutional obligation of the State, has to be kept in view. It is necessary that a time-bound plan for providing these services should be chalked out keeping in view the recommendations of the Committee as well as the requirements for ensuring availability of proper medical services in this regard as indicated by us and steps should be taken to implement the same.” (emphasis supplied).

Consequently, right to health and health care access are a part of Articles 21, 38 and 46 of the Constitution. Accordingly, every person has a fundamental right to quality health care which is also affordable, accessible and compassionate.

### **Whether the Supreme Court has Diluted the Right to Health**

The argument that the right to health as envisaged under Article 21 has been diluted in later decisions of the Supreme Court in **State of Punjab & Ors. vs. Ram Lubhaya Bagga**<sup>19</sup> and **Confederation of Ex-servicemen Associations and Ors. vs. Union of India & Ors.**<sup>20</sup> is not

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<sup>18</sup> Supra

<sup>19</sup> Supra

<sup>20</sup> Supra

correct.

It is pertinent to mention that judgments of Supreme Court in *Pt. Parmanand Katara*<sup>21</sup> and *Paschim Bangal Khet Mazdoor Samity and Others*<sup>22</sup> have not been overruled till date. In fact, in the subsequent Constitution Bench judgment in the case of *Confederation of Ex-servicemen Associations and Ors.*<sup>23</sup> the Supreme Court reiterated that right to medical aid is a fundamental right of all citizens guaranteed by Article 21. The Constitution Bench only held that the contributory scheme framed by the Government qua ex-service men, under which they had to pay one time contribution, was constitutionally valid. In the opinion of this Court, if a class or category of its citizens can afford to pay or partially pay for their medical treatment because of their economic background, Government can certainly frame a contributory scheme for medical treatment.

### **Whether Availability of Finance a Relevant Factor**

Undoubtedly, availability of finance with the Government is a relevant factor. Courts cannot be unmindful of resources and finances. No court can direct that entire budget of a country should be spent on health and medical aid. After all competing claims like education and defence cannot be ignored.

Consequently, courts cannot direct that all inhabitants of this country be given free medical treatment at state expense. Even if such a direction were issued it would not be implementable as there would be neither infrastructure nor finance available for compliance of the said direction.

### **(A) However Core Obligations Like Access To Essential Medicines Are Non-Derogable.**

At the same time, no Government can say that it will not treat patients with chronic and rare diseases due to financial constraint. It would be as absurd as saying that the Government will provide free treatment to poor patients only for stomach upset and not for cancer/HIV/or those who suffer head injuries in an accident!

Disease is a natural catastrophe that fells its victims unpredictably. The right to adequate health care flows from the sanctity of human life and the dignity that belongs to all persons. Health is a fundamental human right, which has as its prerequisites social justice and equality. It should be accessible to all.

Healthcare access is the ability to obtain healthcare services such as prevention, diagnosis,

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<sup>21</sup> Supra

<sup>22</sup> Supra

<sup>23</sup> Supra

treatment and management of diseases, illness, disorders, and other health-impacting conditions. For healthcare to be accessible it must be affordable and convenient.

This Court is of the view that core obligations under the right to health are non-derogable. This minimum core is not easy to define, but includes at least the minimum decencies of life consistent with human dignity. No one should be condemned to a life below the basic level of dignified human existence.

## **VIII. CONCRETE JUDGEMENT**

### **(A) Judgement in Rem**

This Court is of the opinion that core duties under the right to health will be non-derogable. This minimum core, however isn't simple to specify, but comprises at least minimum decencies of life in line with human dignity. Nobody ought to really be condemned to a lifetime below the essential amount of dignified human presence.

From the ruling of the Court, Article 21 of this Constitution evidently imposes a responsibility on the Government to take whatever steps are essential to make certain that everybody has access to medical facilities, services and goods in order they are able to enjoy, whenever you possibly can, the greatest possible standard of physical and emotional wellness. A fair and reasonable access to lifesaving drugs is essential to protecting and promoting the right . Which usually means that Government has to at the bare minimum ensure that people have access to medications that are essential even for rare diseases such as enzyme replacement for Gaucher. Availability of a rather high priced medication virtually causes it to be more inaccessible.

Government can't cite monetary crunch for grounds never to satisfy its duty to guarantee accessibility of drugs or to embrace a course of actions to deal with rare diseases.

### **(B) Judgement in Personam**

From the ruling of this courtroom, no other government can turn out from its center duty of ensuring that the right of access to medical or healthcare facilities for vulnerable and marginalized section of society like the petitioner by saying it can't afford to give treatment for chronic and rare diseases.

As health is a State subject, the current request is discarded with a way to the Government of NCT of Delhi, to release its constitutional responsibility and supply the petitioner with enzyme replacement therapy in AIIMS free of cost and when he needs the same.

## IX. THE CHERRY ON THE CAKE

This Court is also of the view that the practice of 'giving'/donation needs to be exhilarated by the Government. Adequate steps have to put in place to emphasise, popularise and facilitate the process of giving.

The Central and State Governments can certainly tap the resources of the civil society to provide healthcare access to the poor and unprivileged. The Governments can and should appeal contributions to the healthcare sector, both in cash and kind. Both corporate social responsibility and contributions need to be made particularly attractive for pharmaceutical and other companies involved in this sector, as the drugs, implants and devices required are often very expensive and inaccessible to the common man.

### (A) Promote the 'Corporate Social Responsibility'

Section 135 of the Companies Act, 2013 stipulates that a company having a net worth of more than Rs. 500 crores or turnover in excess Rs. 1,000 crores or a net profit of Rs. 5 crores during a financial year must spend at least 2% of its average net profits during the last three financial years on CSR activities covered in Schedule VII of the Companies Act, 2013.

Prior to the enactment of this new Companies Act of 2013, there existed only a set of Voluntary Guidelines issued by the Ministry of Corporate Affairs in 2009 and Schedule VII of the Companies Act, 2013 permitted companies to carry out CSR activities under ten heads which included "reducing child mortality"(at Sr. no. 4 of the un-notified Schedule VII) and "combating HIV, AIDS, malaria and other diseases" (at Sr. no. 5 of the un-notified Schedule VII).

However, when Schedule VII was notified on 27th February, 2014 these two entries were inexplicably dropped from the list of permitted CSR activities. The only area under the then notified Schedule VII was "preventive healthcare". Since the notified Schedule VII would have closed the CSR funding route as an option to sponsor treatments for rare diseases, this Court vide its order dated 28th February, 2014 directed the Ministry of Corporate Affairs to re-examine the matter.

The Ministry of Corporate Affairs filed a letter dated 24th March, 2014 before this Court stating *"Ministry of Corporate Affairs has decided to amend the Schedule VII of the Companies Act, 2013 as 'promoting health care including preventive health care'. This would encompass the entire health care area, including the treatment of diseases etc. "*

On 28th March, 2014, the Ministry of Corporate Affairs filed an affidavit elucidating the scope

of the term "normal course of business" used in Rules 4 and 6 of the Companies (Corporate Social Responsibility Policy) Rules, 2014, by giving the following example:-

*"...a pharmaceutical company donating medicines/drugs within section 135 read with Schedule VII to the Act is a CSR Activity, as the same is not an activity undertaken in pursuance of its normal course of business which is relatable to health care or any other entry in Schedule VII."*

### **(B) Governments Advised To Consider Expanding Their Health Budget**

The court also notes the fact that it is unfortunate that even after sixty-six years of independence, universal medical healthcare is still a distinct dream. Even today, economically weaker sections of the society do not have access to free medical treatment.

The Court expressed its view that Government needs to seriously consider expanding its health budget if their right to life and right to equality as enumerated in Articles 14 and 21, are not to be rendered illusory. If poor patients are to enjoy benefit of recent innovations in the medical field, like robotic surgery, genome engineering the Government must immediately think of increasing its investment in the health sector.

## **X. CONCLUSION**

To conclude, today, on account of lack of Government planning, there is '**pricing out**' of orphan drugs for rare and chronic diseases, like Gaucher. The enzyme replacement therapy is so expensive that there is a breach of constitutional obligation of the Government to provide medical aid on fair, reasonable, equitable and affordable basis. By their inaction, the Central and the State Governments have violated Articles 14 and 21 of the Constitution.

Just because someone is poor, the State cannot allow him to die. In fact, Government is bound to ensure that poor and vulnerable sections of society have access to treatment for rare and chronic diseases, like Gaucher especially when the prognosis is good and there is a likelihood of the patient leading a normal life. After all, health is not a luxury and should not be the sole possession of a privileged few.

Although obligations under Article 21 are generally understood to be progressively realizable depending on maximum available resources, yet certain obligations are considered core and non-derogable irrespective of resource constraints. Providing access to essential medicines at affordable prices is one such core obligation.

Since a breach of a Constitutional right has taken place, the Court is under a duty to ensure that effective relief is granted. The nature of the right infringed and the nature of the infringement provides guidance as to the appropriate relief in a particular case.

As health is a State subject, the present petition is disposed of with a direction to the Government of NCT of Delhi, to discharge its constitutional obligation and provide the petitioner with enzyme replacement therapy at AIIMS free of charge as and when he requires it.

Also, since as the concept of CSR is still at a nascent stage and there is no mechanism in place which popularizes and facilitates donation, this Court is of the view that State must bear the burden of the treatment.

## **XI. SUGGESTIONS**

The following are few suggestions that were brought by the Court in this judgement which are notable and the court through this judgement suggests that both the Central and State Governments should consider the following recommendations:

1. All government hospitals could have a separate CSR/ Charitable entity/account wherein donations can be received. The donations could be subject to an audit.
2. Each hospital could have a designated officer, to whom applications for assistance can be made by patients in need. The decision to whom financial assistance could be provided, be left to the Medical Superintendent/CEO of the Hospital along with Head of the Departments. Delhi could be adopted as the first model state.
3. The Ministries of Corporate Affairs and Finance could consider providing extra credit (for instance increased credit) for donations in certain sectors, such as health.
4. The Government could adopt a holistic approach to facilitate donations, so that the tax regime supports the said efforts.
5. All donations in cash and kind must be accounted for, with complete transparency to ensure no misuse or misappropriation of donations.
6. Government hospitals could put up list on the State Department of Health website of the drugs, implants and devices they require for EWS/BPL patients. This way people would donate as per the need of each hospital. This could be revised on a monthly basis.
7. The State Government may put up a list of drugs, implants and devices which are excluded from its budget for which donations would be welcome.
8. Both the Central and State Governments could create a revolving fund to take care of recurring expenditure of patients suffering from chronic and rare diseases.

9. The Government could constitute a High Powered Inter-disciplinary Committee to:
- Develop and update a list of guiding principles/best practices in the area of donations in healthcare.
  - Develop a policy for tackling rare diseases and promoting the development of orphan drugs.
  - Evolve new and innovative methods for attracting spending in the area of healthcare.
  - This Committee could have representatives from various State and Central Government departments, private and government hospitals, non-governmental organizations working in the area of healthcare, representatives of patients' rights groups, representatives of pharmaceutical and other companies in the healthcare sector.

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