**IN THE HIGH COURT OF MADHYA PRADESH, BENCH AT INDORE.**

WRIT PETITION (PIL) NO. **\**2020

 **PETITIONER:** Sarang Gaithane S/O Sudam Gaithane

 Age – 45,

 Occupation – Social Worker

 Address – Balpur Badganga,

 Indore (M.P.)

 VERSUS

 **RESPONDENTS:** 1. Chief Secretary, Health and Family Welfare Department, Indore (M.P.)

 2. Collector

 District, Indore (M.P.)

 3. Chief Medical and Health Officer

 Indore (M.P.)

 4. The Municipal Commissioner,

 Indore (M.P.)

**WRIT PETITION UNDER ARTICLE 226 OF THE**

**CONSTITUTION OF INDIA (PIL)**

 **R/w under Article 21 of the Constitution of India.**

1.**Particulars of the cause/order against which the petition is made:**

1.1. Date of Order: Nil

1.2 Passed in (Case or File Number): Nil

1.3 Passed by: Nil

1.4**. Subject-matter in brief:**

1. Leprosy is an infectious disease caused by a slow-growing type of bacteria called Mycobacterium Leprae (M. leprae). Leprosy is also known as Hansen's disease that causes severe, disfiguring skin sores and nerve damage in the arms, legs, and skin areas around the body. The disease has been around since ancient times, often surrounded by terrifying, negative stigmas and tales of leprosy patients being shunned as outcasts. Outbreaks of leprosy have affected, and panicked, people on every continent. Leprosy mainly affects the skin and nerves. It has a low mortality but high morbidity, making the patient physically, socially and psychologically handicapped, especially with the age-old stigma associated with the disease.
2. Since most of the patients don’t have fingers and properly functioning limbs, they cannot avail proper employment and hence resort to begging as a means of earning income. This does not supply them with adequate money to support their medical bills and they cannot approach private clinics and rely solely on the aid of the Sewadoots (Nurse) appointed to look after them.
3. Leprosy patients suffering from the disease from time immemorial stay wounded, their wounds never completely heal and rather keep increasing. And thus, they require regular dressing and medication. The amount of medical supplies provided to by the state is only sufficient for a week, whereas it should last a month. The same facilities are not adequately provided by the state. This includes items like medicine, cotton, gauze, ointment etc.
4. All the shelters including the ones in areas of Indore, Ratlam, Sendhwa, Ujjain, etc. have a total of approximately 1000 patients all together, and the facilities provided are not proportionate to the needs of the people and this results in the spread of their infections rather than the contraction of it.
5. Most of the government documents require biometric scans, and a majority of the patients are handicapped in the way such that their fingers have fallen off and cannot avail these services.
6. There are also problems relating to hygiene of the colonies formed by people with leprosy. There are problems such as uncovered pipelines, which pose a serious threat to leprosy victims, as they have open wounds that may contact infections and fester.
7. The petitioner has provided a large number of applications and requests addressed to respondents for services, pension, medical facilities, and hygienic conditions of colonies, all of which are attached in the annexure, and none have been replied to till date.

2.**The antecedents of the petitioners:**

2.1 1 That, the petitioner is a permanent resident of M.P. and citizen of India, The petitioner is a Social Activist and works on leprosy related issues while being a leprosy patient himself.

2.2 That, the present petition under article 226 of the constitution of India are being filed by way of PIL and the petitioner have no personal interest.

2.3 That, the petitioner is filing the present petition on his own and not at the instant of someone as the litigation cost including the advocate fee and the travelling expenses of the lawyers are being borne by the petitioners himself.

3**.Facts of the case:**

3.1 Petitioner and other leprosy patients as such the cause of action for filing this writ petition arises within the territorial jurisdiction of this Hon’ble Court.

3.2 That, the national survey for determining new cases relating to detection rate of leprosy and to publish and bring in the public domain the reports of national sample survey on leprosy conducted in 2010-2011 and further to conduct regular and sustainable massive awareness campaigns for the general public to dispel the fear associated with leprosy and support and encourage the people afflicted with the said disease to lead a life of equality and dignity.

3.3 That, leprosy is back in India. Health officials and activists celebrated 13 years ago when India announced that leprosy had been eliminated as a public health concern. Alarm bells rang as the Central Leprosy Division of the health ministry reported that 135,485 new leprosy cases were detected in India in 2017. That meant every four minutes somebody was diagnosed with leprosy in India. This is nowhere close to elimination. Also, there are many new children found who were identified with this disease, and the number is continuously rising.

3.4 That, of the new cases detected, nearly half (67,160) have been diagnosed at an advanced stage, and the number of new detections is high. “Pockets of high endemicity report thousands of new cases every year,” the World Health Organization (WHO) noted in 2016, adding that in 2015, India had accounted for 60% of the global total of new cases.

3.5 That, people afflicted with leprosy are considered as outcasts by the society and do not gain acceptance by them and as such, are forced out of the society, wherein they band together and form colonies where people with leprosy and their relatives live together. These colonies house roughly 1000 patients and their families.

* + 1. Colonies within Indore and surrounding areas are stated below –

|  |  |  |
| --- | --- | --- |
| **S. no.** | **Name of Colony** | **Approximate strength** |
| 1 | Sahiram Avtar Kusth Seva Samiti | 50 victims |
| 2 | Sant Gyaneshwar Kusth Ashram, Mahesh Yadav Nagar | 40 victims |
| 3 | Mahasaraswati Kusth Ashram, Bhagat Singh Nagar | 15 victims |
| 4 | Ram Avtar Kusth Ashram, Alwasa | 30 victims |
| 5 | Arunadaya Kusth Ashram, Jambudi Habsi | 100 victims |
| 6 | Maa Bhawani Kusth Ashram, Rajendra Nagar | 20 victims |
| 7 | Esawas Colony, Maruti Nagar | 50 victims |
| 8 | Kusth Sewa Sanstha, Nanda Nagar | 35 victims |
| 9 | Srinath Dham Kusth Ashram, Machala | 30 victims |
| 10 | Ramdas ka Maha (Gareeb Khana)  | 10 victims |
| 11 | Palia Kakad | 30 victims |
| 12 | Murti Nagar Colony | 20 victims. |
|  | **Ujjain** |  |
| 13 | Baba Ramdev Kusth, Ambukhedi | 80 victims |
| 14 | Sadananda Mahadev Kusth Rogi, Dewas Gate | 100 victims |
|  | **Dhar** |  |
| 15 | Anand Nagar Kusth Ashram | 125 victims |
| 16 | Khanpura Kusth Ashram | 150 victims |
|  | **Ratlam** |  |
| 17 | Sitlamata Kusth Ashram, Motinagar | 50 victims |
|  | **Badwani** |  |
| 18 | Ashagram Kusth Ashram  | 50 victims |
|  | **Sendhwa** |  |
| 19 | Harsh Nagar Kusth Ashram | 100 victims |

* 1. That, accordingly it is found that people suffering from leprosy, in which the affected areas like hands, shoulders, fingers, toes etc. become senseless and tendons swell up and may even fall off.
	2. That, the people suffering from leprosy have wounds that never fully heal, and to cover their open wounds, they need a constant supply of bandages, cotton, ointment and gauze. The amount of dressing material that they get from the government is nowhere near the amount needed. An application for the same was applied by them members of various colonies on 11/07/2019, all of which have been attached in **Annexure P/1**
	3. That, these fallen off fingers do not grow back, and for a lot of patients who are illiterate and would otherwise rely on verifying their identities by their fingerprints, are rendered incapable of the same. Because they don’t have fingers, they cannot verify their identities for Aadhar, and to collect their rations from government Control centers. Due to this, they not only lack medicinal facilities, but also basic amenities like food.
	4. That, it is due to the same reason that many people have had their pensions pending for years. There have also been instances when victims had gone to collect rations, they were denied on the grounds of them being unable to provide rations without proper verification (usually through biometrics such as thumb prints). Apart from the same, they also do not receive other benefits, and are robbed of the same due to issues stemming from the disease.
	5. That, due to their unusual circumstances and the fact that they are left crippled due to their disease, they are denied most labor or skilled work, and as such, have to resort to begging for money to make ends meet.
	6. That, the people who volunteer (generally females) for aiding in the medical care of the patients, are called Sewadoots. While they are paid for their work, the wages are extremely meagre. They are paid somewhere near Rs 900/- for extremely taxing and crucial work. This wage rate has been constant for the past 5 years despite the growing rates of inflation in the country. concerns regarding the same have been raised to the Respondent No.2, applications for which have been attached in the **Annexure P/2** dated 11/7/2019.
	7. That, representation notice has been given to the Respondent No.2 on multiple occasions, the most recent being on 2/7/2019 by the Sheetla Mata Kusth Dham Sewa Samiti but no hearing had been scheduled. A list of all the signatories of this letter who are also a part of the society has been attached in the list below with signatures in **Annexure P/3**

|  |
| --- |
| Name of signatory |
| Suraj Bai | Kumari Deshmukh |
| Shambhu Nanda | Ashok Deshmukh |
| Baibi Ramesh | Narayan Bheel |
| Bapu Lal Prajapati | Jamna Bai Bheel |
| Moti Pargi | Kamla Bai |
| Durga Pargi | Bherulal Kodar |
| Manju Bai Bhima | Mangilal Veerji |
| Mangu Bae | Kanchan Bai |
| Babu Jiwa | Suneeta |

* 1. That, Writ Petition (Civil) number 767 of 2014 – Pankaj Sinha V. Union of India and Others, filed in the Supreme Court under Article 32 of the Constitution of India has been in the interest of leprosy patients and has provided several guidelines as to the treatment and awareness programs of affected community. The Judgment (date) has been attached in **Annexure P/4** for reference, which has a total of 15 points for the betterment of people suffering from leprosy, which include aspects such as drugs and treatment being provided free of cost, awareness campaigns, treatments in hospitals without any discriminations, medical consultations, education for children whose family members are affected by leprosy, issuance of BPL cards to avail benefits of AAY schemes, provision of MCR footwear, etc.
	2. That, people afflicted with leprosy were wrongly given APL cards when they should have been given BPL cards. Due to this, people who are economically weak and have leprosy cannot avail all the benefits of various schemes of the government that they otherwise would. Applications by ‘Jai Shree Sai Ram Avatar Kusth Sewa Samiti’ as well as other letters addressed to the collector regarding the same, as well as all the signatures of the signatories have been attached in **Annexure P/5** This letter is dated on 11/07/2019 and on 24/07/2019 they sent another representation to Respondent no.2 that their BPL card should be converted to Antyodaya Card.letter dated 24/07/2019 annexed herewith as **Annexure P/6**
	3. That, a letter dated 11/07/2019 issued by the ‘Sant Gyaneshwar Kusth Sewa Samiti’ brings to fore an issue faced by the society where an open drainage pipeline right next to the premises which poses a major sanitary issue. As has been pointed in the letter, children specifically are at risk due to the same, and the petitioner has given a application to Respondent No.4 to take some action against the same, keeping in mind the aforementioned Supreme court judgement and has requested for the construction of a wall or some form of cover for the drainage. The letter with the signatures of the signatories has been attached in the **Annexure P/7**
	4. That, Sahyog Kustha Nivaran Sangh on 17/01/2019 sent a representation to Madhya Pradesh shashan Bhopal in which they asked for a pension of 2000rs per month. **Annexure P/8**
	5. That, as mentioned in an order issued by the Deputy Director of Health Department, Bhopal under order number F-268/2019/35 dated 09/01/2019 which states that all the people suffering from leprosy are entitled to a pension of Rs. 2000 each, but the same has not been enacted upon, and an application from the ‘Sahyog Kusth Nivaran Sangh’ dated 17/01/2019 which asks for the implementation for the same, have both been attached in the **Annexure P/9**
	6. That, **Annexure P/10** contains pictures of Sewadoots treating the Leprosy patients.
	7. That, **Annexure P/11** contains pictures of Leprosy Patients.
	8. That, The Rights Of Persons With Disabilities Act, 2016 states that Leprosy Patient also comes under the term Disabled. The above mentioned act is annexed in **Annexure P/12** Persons with disability should get proper community centers with good living conditions in terms of safety, sanitation, healthcare and counseling; Free education up to 18 years; disability pension; Unemployment allowance; comprehensive insurance scheme**.**
	9. That, people of our society still consider leprosy patients untouchable. They make a living by begging, and are forced to make their colonies separate and live together, away from the rest of the society.

**4.Source of information**

The information has been provided by newspapers and some of the surveying done by the Petitioner who is a social worker went to Sarang NGO met with some of the people suffering from leprosy and took the photographs and documents of them. Information collected from some Kustha seva Samiti organizations.

5.  **Nature and intent of intent of injury caused.**

The people and children suffering from leprosy and their family have to suffer great losses due to the negligence of respondents and government employees, doctors and hospital staff.

6. **Issue was neither dealt nor decided**.

The issue was neither raised nor decided in any petition filed by the petitioner.

7. **Any representation made.**

A representation was made as per **Annexure P2, P3, P4, P8** along with receipt on d. But the government and other respondents are already aware of these issues through social activists, print media and electronic media.

8.**Grounds urged**

The petitioner therefore, finding no other speedy, efficacious and alternative remedy craves indulgence of extraordinary jurisdiction of this Hon’ble Court to interfere in the matter of greater interest of justice.

1. As part of a series on the 21 disabilities included under the Rights of Persons with Disabilities (RPWD) Act, 2016, today we talk about people whose leprosy has been cured.
2. These are people who have received treatment for leprosy and are cured but have some or the other disabilities due to the disease. The disease is long term and can affect the patient for years and sometimes without any symptoms, with mostly undetectable damage. It can affect the nerves, skin, eyes, and lining of the nose. Another aspect of the disease is that wounds caused due to the disease never fully heal, and need to be cleaned and bandaged thoroughly.
3. Leprosy is spread through contact with the infected person via cough or fluids from the nose of an infected person. Leprosy occurs more commonly among people who are living in poverty, mostly due to unhygienic conditions and a general lack of awareness.
4. Leprosy can affect people of all ages. Despite the condition being curable, there is lot of stigmata and shame attached to it in our society. People tend to hide their symptoms due to fear of being treated with disdain. In most cases this worsens the infection and the patient in question fails to get treatment in time. This results in severe health complications and may lead to permanent, incurable disabilities.
5. Leprosy cures were covered under the original nineteen ninety-five act. It has continued in the RPWD Act as well. But the fact remains that their conditions continues to remain the same. Stigma plays a major role in this. Apart from the pre-prescribed treatment, measures aimed at rehabilitation are inadequate.
6. Several instances have come to forefront highlighting that people affected with leprosy are being provided with APL cards and not BPL cards which prevents these people from claiming benefits under various schemes brought out by the government, such as the Antyodaya Anna Yojana (AAY), which again deprives this section of the population from claiming their right to food. Deprivation of housing and other basic civic amenities, adequate sanitary facilities and rehabilitation programmes are yet other serious concerns which, if not addressed, would lead to the entire reformatory process suffering a huge setback.
7. Medicines provided to the patients are, more often than not, insufficient. This is not applied only to MDT medicines, but also general medicinal supplies. Leprosy patients have wounds that never fully heal, and need to be constantly dressed, and the dressing needs to be changed regularly. For the same, the government does provide bandages and other supplies, but they are usually inadequate, to only about 2 tubes of antibacterial cream, a roll of cotton, a roll of gauze to be distributed amongst 50 patients. Due to this, volunteers end up going through all the supplies within 2 changings of the bandages.
8. It is urged that the staff of PHCs display sheer lack of sensitivity while dealing with patients affected with leprosy as a consequence of which the level of stigma and isolation still prevails amongst the said patients. Several incidents have also been reported which have brought to light the discriminatory treatment meted out by the Government hospitals to leprosy affected pregnant women and cases wherein women have been refused treatment solely on account of being affected by leprosy. Another aspect, that is, the area of education has also been brought forth by the petitioners. It has been urged that lack of adequate education facilities would further magnify the sense of insecurity and stigma prevailing amongst the personsaffected with leprosy. For any development to take place, the first step would be in the direction of ensuring quality education for the children who are the wards of people affected with leprosy.
9. Patients with leprosy stand a chance to lose their fingers and sometimes lose sensitivity in their limbs. This negatively affects their chances of employment, since they are left incapable of both physical as well as skilled labour. Due to the same, they are reduced to either extremely low paying jobs, or have to beg to make a living.
10. The discriminatory behaviour is done while examining and treating leprosy patients. They are not taken to general wards and are not allowed to take OPD services.
11. Health care to leprosy patients, at both Government as well as private run medical institutions, must be such that medical officials and representatives desist from any discriminatory behaviour while examining and treating leprosy patients. Treatment of leprosy should be integrated into general health care which will usher in a no-isolation method in general wards and OPD services. In particular, it must be ensured that there is no discrimination against women suffering from leprosy and they are given equal and adequate opportunities for treatment in any hospital of their choice. To this effect, proactive measures must be taken for sensitization of hospital personnel.
12. The Judgement passed by the Honourable Supreme Court for the Writ Petition (Civil) number 767 of 2014 – Pankaj Sinha V. Union of India and Others gives out 15 comprehensive points for the betterment for the people afflicted with leprosy and has not been complied to the respondents.
13. Apart from all this the complications faced by people suffering from leprosy are as follows-
14. Leprosy can permanently damage the skin, cause blindness or glaucoma. Disfiguration of the face (including permanent swelling, bumps, and lumps)
15. Erectile dysfunction and infertility in men
16. Kidney failure
17. Muscle weakness that leads to claw-like hands or an inability to flex the feet
18. Permanent damage to the inside of the nose, which can lead to nosebleeds and a chronic, stuffy nose
19. Permanent damage to the nerves around the brain and spinal cord, arms, legs, feet, and eyes.
20. Nerve damage can lead to a loss of one’s ability to feel physical elements. A person with leprosy-related nerve damage may not feel pain when the hands, legs, or feet are cut, burned, or injured otherwise, or feel anything altogether.

9. **Details of remedies exhausted**

No remedies exhausted except this petition.

10. **Delay if any in filing the petition.**

There is no delay in filing the petition.

11.

12. **Interim Order/writ, if prayed for:**

A. It is urged that medicines and other dressing material be provided as soon as possible to the clinics in proportionate quantities to the number of patients that they are dealing with to ensure a continuous and surplus supply of the same.

B. Problems relating to sanitation of colonies of patients should be taken care of with the utmost priority as the open drainage system is extremely hazardous for these patients with open wounds and the children who live with them.

C. Aadhar cards and other documents that require verification should have an option of verifying the identity of the people solely through retinal scans in case the person in question is physically incapable of verifying their identity through biometric scans which is the case with leprosy patients whose fingers fall off as their disease progresses.

13. **CAVEAT**:

That, no notice of lodging a caveat by the opposite party is received.

Indore Submitted By:

DATE: 09 /01/2020 Advocate for The Petitioner

 Shanno Shagufta Khan