**Project Proposal: ‘TRISHLA CEREBRAL PALSY VILLAGE’**

**Trishla Foundation, Prayagraj, UP, India**

A team of motivated personnel, under the patronage of Dr. Jitendra Kumar Jain, Orthopedic surgeon started their work towards the well being of children with cerebral palsy at Prayagraj (Allahabad), Uttar-Pradesh, India since 2005. TRISHLA FOUNDATIONwas founded and registered under the India Trust Act 1882 on 12th April 2014 to broaden the horizon of rehabilitation & social development of the children suffering with various Locomotor disabilities.

**Mission of Trishla Foundation:**

*“Our mission is to integrate every child with Neuro-muskuloskeletal disability especially cerebral palsy to the mainstream society by providing them comprehensive rehabilitation care.”*

**AIM:**

* To provide multimodal advanced medical and rehabilitation facilities to the children suffering with various locomotors disabilities irrespective of their socio-economic status.
* To provide appropriate training to rehabilitation specialists, social workers & parents towards advanced care of children with cerebral palsy & other childhood physical disability.
* To develop a centralized highly advanced rehabilitation centre cum research institute at Prayagraj and to develop satellite / associate centres in other parts of India.
* To create awareness among disabled children care takers, general public and media about the recent advancements in the management of various Orthopaedic disabilities especially cerebral palsy by organizing camps, publishing articles and documentaries on paediatric disability.

**What is cerebral palsy?** Cerebral palsy is a group of neuromotor problems that is characterised by difficulty in ambulation & often accompanied with problem in sensation, cognition, perception, communication, vision, speech, hearing, immunity, epilepsy, feeding, growth etc.

* It is one of the common causes of severe physical disability in childhood. It occurs because of “brain insult” during early phase of life from foetal life to 2.5 years of age.
* Problems like severe jaundice, intrauterine infection, trauma, genetic problem, hypoxia and many unknown causes can cause insult to immature brain during early age of life.
* Low birth weight & premature born babies are more prone to cerebral palsy. These children are unable to achieve “developmental milestones” as other normal children.
* These children can be identified at early age by identification of the above-mentioned history, delayed milestone, abnormal social smile, abnormal reflexes, abnormal tone, abnormal movement, abnormal growth pattern and delay in ambulation.
* Brain insult is static bur their disabilities can increase, decrease or static depending upon environment and treatment intervention.
* With early intervention by multimodal therapeutic approach, more than 80% children can have good quality of life & More than 60% can have ambulatory life. Mental retardation is found in only 40% cases.
* These children need medical care by team of medical & rehab specialists which include physiotherapists, occupational therapists, speech therapists, special educators, an orthopaedic surgeon, a neurologist, a paediatrician etc.
* Cerebral palsy can’t be cured but we can decrease the disability to an extent that most of them can become self dependent and can be integrated in main stream schooling & society.
* They can have professional degree, can have job, marry and live a long life.

**Worldwide scenario:** According to **Stanley (2000)** Cerebral palsy (CP) is the most common congenital neurologic disorder. The world-wide prevalence of cerebral palsy is 2-2.5/1000 live births. Worldwide more than 15 million people are affected with cerebral palsy. In developed countries, advanced facilities like institutional care, proper documentation, gait labs, social security, inclusive education, advanced rehab modalities are available. In the last two decades many new rehabilitation techniques have been discovered which has resulted in better living standards of these children.

**Indian scenario:** In India, around 30 Lac children are affected by cerebral palsy. Most of them remain confined to home due to lack of awareness in society and lack of advanced rehab care. The disorder is commonly taken as a God curse with a belief that such children can neither be socially inclusive nor be successful in life. Out of those untreated, more than 50% die before reaching adulthood. Multiple hurdles remain in successful treatment of CP children in India like lack of clear-cut guidelines for treatment, long period of rehabilitation, requirement of multiple dedicated personnel, low research activity, lack of training centers for therapists and specialists in advance modalities of rehabilitation, inadequate facilities for life time care, presence of very few specialized centers, late presentation for treatment, poor financial status etc. There are minimal government supportive programs, no government policies for these children in terms of education and employment.

Parents of such children often wander from place to place in search of a suitable treatment. Some resort to traditional therapy which is in fact harmful for such children. They face many difficulties because of lack of standardized treatment regimen, non availability of advanced and multimodal rehab measures, difficulty in getting consultation from various specialty fields of medicine in a single place, difficulty in staying away from their home at rehab centre for long term treatment and no knowledge about future directions and prognosis of the disorder. Almost all of them face financial problems in the long run. Many face psychological problems, and without clear medical advice they stop treatment all together.

There are very few places of rehabilitation for cerebral palsy affected individuals in India especially in North India. The number of children with Cerebral Palsy in this region is quite high, owing to its large population and presence of risk factors.

Trishla Foundation is one of the first of its kind in Prayagraj, providing comprehensive rehabilitation services to such children. At present children with cerebral palsy are coming from nearly every state of India and many other countries. On an average, more than 200 children are visiting our centre every day for therapy. This number is increasing as awareness about our centre facilities and activities is spreading. We believe that, with the current increment pattern, nearly 500 children will be attending our rehab centres on daily basis in near future. This demands a substantial increase in the facilities of advance rehab measures along with accommodation for parents and children who come from distant places under one umbrella.

**Role of Trishla foundation:**  Trishla foundation is receiving children with cerebral palsy from all socioeconomic backgrounds irrespective of cultural, financial & geographical barriers. With increasing awareness in society, the children with cerebral palsy are recognised early and are being referred to our centre from many parts of India. The Foundation guides the parents of such children for proper treatment using latest treatment modalities available.

**Strategies for Achieving the Goals:**

1. To create awareness about comprehensive rehabilitation and early diagnosis of cerebral palsy through awareness camps and educational programs.

2. Training of physiotherapists, speech therapists, special educators and orthotic technicians specifically for cerebral palsy.

3. Training & motivating parents in therapy program for their own child and solving the problem of activities of daily living.

4. To provide treatment to children from poorest class society with minimal & affordable expenses.

5. To organize events like conferences, workshops, seminars for awareness and training to all concerned like therapist, social workers, parents etc.

6. Development of a world class rehab centre having advanced equipments, gait lab and facilities for advanced therapeutic techniques.

7. Development of advanced institution for training and research in the field of physical disability.

8. Development of inclusive education school and recreation centre for children with special needs.

9. Conducting Orthotics workshop for development of orthotics and assistive devices to cater specific needs.

10. Development a CP home for temporary stay arrangement of parents along with their children.

**Present Activities of the Foundation:**

Various activities which are being done for betterment of these children at Trishla foundation are as follows:

1. Trishla Activity Centre:- This centre was established with the objective of providing advanced rehabilitation for training in activities of daily life.

2. Trishla Early Intervention Centre:- This centre is providing early intervention to very young children below 5 years of age, since they need different approach.

3. Trishla Rehab centre: Trishla rehab centre was started with the aim to provide regular therapy to children affected with cerebral palsy and other physical disabilities.

4. Trishla advance rehab Centre:- This centre was established with aim to cater growing number of children.

5. Special education Centre- Two special education teachers were appointed with the aim to provide special education, hand therapy and to improve coordination.

6. Speech therapy Centre- Three speech therapists provide speech therapy to these children.

7. Trishla orthotic workshop: Trishla orthotic workshop is meant to provide orthotics “brace” to children with cerebral palsy.

8. Trishla Medical Card:- We issue this card to children and adults with chronic neuro-musculoskeletal disability from poor socioeconomic background. This medical card helps the patient from very poor socioeconomic back ground in getting consultation free of charge and rehab facilities at very subsidized charges.

9. Niramaya health card- We started helping children to get registered under Niramaya health scheme, which is issued by the national trust, ministry of social justice & empowerment, Govt of India.

10. Camps:- The Foundation is conducting free check up , training & awareness camps in different parts of the country with a mission to not only create awareness but also to provide training to parents and therapists for rehabilitation of the children with cerebral palsy.

11. CME, workshop, seminar and conferences:-Regular CMEs, conferences, seminar etc. are being organized to update specialists, social workers about latest developments in cerebral palsy. We also organize special symposium for parents of CP Children to make them aware about treatment and govt schemes available and precautions to be taken for a CP child.

12. Social Activities:-We organize regular social activities like Holi Milan, Magh Mela Visit, New year picnic, sports activity, wheel chair cricket tournament, cultural events etc. involving parents and children of our foundation to make them feel that they are integral part of this society.

13. Parent’s training. Parents are given training in home based therapy and ADL to sustain the long term treatment of their own child.

14. Therapists training: Therapist & other paramedical staff are given regular training in rehab techniques and latest updates.

15. Associated Rehab centres: Trishla foundation provides supervision; guidance and technical support in advance rehab facilities at peripheral centres in other areas of the country.

16. Indoor & Outdoor activities are the regular feature of our foundation. It helps the children in developing confidence, building up relationship and intermingling in society.

**Proposed project: Setting up Trishla CP Village:**

**\*** Many cerebral palsy individual require lifelong care. The incidence is almost same since several decades throughout the world. Prevention strategy aimed at proper perinatal care may reduce but not eliminate the incidence. Therefore treatment centres equipped with all the facilities for its management is the need of hour.

\* At present Trishla foundation has been already recognised as a highly preferred advanced rehab centre for children with cerebral palsy in India & abroad. With increasing number of children with CP coming from various parts of India, the foundation is pressurised with the crunch of space, manpower and finance.

\* We propose a plan to set up a CP village where accommodation, treatment, research facilities and manpower all can be smoothly done at one place. The aim is to provide quality medical, surgical, rehabilitation, educational, accommodation and other required facilities all under one roof in a cordial environment.

\* The CP village will have CP Home, Advanced rehab centre, Gait lab, Orthotics workshop, Sports ground, integrated school and training centre and Specialty clinics.

\* In specialty clinic consultants from various subspecialties that require medical attention like vision, hearing, epilepsy, nutrition, mental retardation etc. shall be available under one roof. Some of the proposed consultants are: Paediatric neurologist, Paediatric surgeon, Ophthalmologist, ENT surgeon, Dental surgeon, Dietician etc.

\* Comprehensive rehabilitation by team of Rehab Professionals, Orthotic technician, Speech therapist, Special education teacher, Nutritionist and specialists from various medical and paramedical fields.

\* Outdoor and indoor recreational and sports activities for children with disability.

\* Inclusive education for these children.

**Proposed five year plan:**  Trishla foundation is planning to develop this special village in a phased manner.Initial Land of 1355 Squire meter for proposed CP home in First phase has been lease out to Trishla foundation for 29.5 years by Dr Jitendra Kumar Jain onm 23th july 2018. . This Land is situated at Village Sarai Bahar / Sarai Brisinghpur under Soraon Tehsil Prayagraj District. Land required for other centre in second and third phase will be arranged accordingly as per need.

**Phase 1**: CP home & Temporary rehab centre - Projected time frame 2019-2021.

This is the immediate requirement, since the soaring cost of rental stay at Prayagraj has become a big hurdle for families coming for treatment from far flung places. The centre would be a twin building of four floors each with total building area of 50,000 square feet and will have 78 rooms and rehab centre at ground floor. The plan is to accommodate approximately 78 families. Same floor plan will be for first, second & third floor. Initially ground floor will be used for rehab center, canteen, office & multipurpose shop for parents. But after some time when we buildup second building of rehab center then   it will transferred there then ground floor will be used for parking. Total covered area of one floor will be 12500 square feet

**Phase 2**: Advance rehab centre, Sport ground, Orthotics Workshop & Inclusive education school - Projected time frame 2021-2023.

This centre will be developed near CP home and will have all the facilities of advanced world-class rehab centre. The centre would be a twin building of three floors each with total building area of 60,000 square feet and will have following departments -Department of developmental physiotherapy, gait lab, occupational therapy, speech therapy, yoga, counselling, paediatric neurology, paediatric orthopaedics, audiology etc

First building

Ground floor: Rehab centre for children older than 10 years of age, audiovisual, gait lab, office, counselling centre, nutrition counselling and consultation room for specialists of different departments.

Ist floor: Rehab centre for 5-10 years of age, activity centre, speech therapy centre, special education, occupational activity, hand skill development centre.

IInd floor: Rehab centre for < 5 years of age, extracurricular hall

In addition every floor will have- Assessment cum record room, parents rest room, NDT room, SI Room, audiovisual room

Second building:

* Administrative block containing main office of rehab, finance, building maintenance room, electricity panel and office, office of chairman, secretary, executive officer
* Orthotics Workshop, carpentry workshop
* Seminar hall, library

Inclusive Education School: This would be a Primary school constructed in a separate building.

Sports Ground: We are also planning to set up a sport ground for children affected with different kind of physical disability.

**Phase 3:** Extension of CP home & hydrotherapy pool - Projected time frame 2023-25

In this phase, New CP Home will be constructed for accommodating increasing number of families of CP Children (more than 200). Swimming pool will also be constructed for hydrotherapy.

CAPITAL EXPENDITURE OF THE PROJECT **:**

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| --- | --- | --- |
| **PHASE I : June 2019 to June 2021 ( 2 years)** | | |
|  | Phase Activity | Cost in Rupees (Approx.) |
| 1 | Construction of CP home | 700,00,000 |
| 2 | Temporary rehab centre | 10,00,000 |
| 3 | Transportation facility | 20,00,000 |
| 4 | Solar Panel | 20,00,000 |
| 5 | Lift | 5,00,000 |
|  | Total | 755,00,000 |

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| --- | --- | --- |
| **PHASE II : June 2021 to June 2024 ( 3 years)** | | |
|  | Phase Activity | Cost in Rupees (Approx.) |
| 1 | Advance Rehab Centre | 1000,00,000 |
| 2 | Orthotic workshop | 5,00,000 |
| 3 | Inclusive education school | 150,00,000 |
| 4 | Solar Panel | 20,00,000 |
|  | Total | 1175,00,000 |

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| **PHASE III : June 2024 to June 2025 ( 2 years)** | | |
|  | Phase Activity | Cost in Rupees (Approx.) |
| 1 | Extension of CP Home | 1500,00,000 |
| 2 | Solar panel | 20,00,000 |
| 3 | Swimming pool for hydrotherapy | 65,00,000 |
|  | Total | 1585,00,000 |

**Other expenditure :**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | In Rupees / year | For 5 years |
| Proposed Staff Salary(Total) | Annual | 100,00,000 | 500,00,000 |
| Furnishing of CP home | One time | 10,00,000 | 10,00,000 |
| Furnishing and equipments for Advance rehab centre | One time | 100,00,000 | 100,00,000 |
| Furnishing of Extended CP home | One time | 10,00,000 | 10,00,000 |
| Maintenance | Annual | 10,00,000 | 50,00,000 |
| Awareness cum free check up Camps | Annual | 5,00,000 | 25,00,000 |
| Total |  |  | 695,00,000 |

**Plan to meet out recurring expenses for sustainability of project**

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| --- | --- |
|  | **Cost of temporary stay** |
| Lower SES | 10% rooms at highly subsidized rate (75%) |
| Upper lower SES | 10% rooms at subsidized rate (50%) |
| Lower Middle SES | 10% rooms at subsidized rate (25%) |
| Upper SES | 70% rooms at full rate |
|  | **Cost of therapy** |
| Lower SES | 10% seats at highly subsidized rate (75%) |
| Upper Lower SES | 10% seats at subsidized rate (50%) |
| Middle SES | 10% rooms at subsidized rate (25%) |
| Upper SES | 70% seats at full rate |

**Registration in government offices detail:**

Office of sub registrar ---- 129/150/343/12/08/2014

Dept of empowerment of person with disability govt of Uttar Pradesh: 3359/2016-17

Niti Ayog : UP/2017/0150433

National trust: UTRI17517078388

**Round the year donation drive for Trishla foundation:**

We hereby request the public and philanthropists to donate for this unique CP village project aspired by Trishla foundation, so that thousands of CP afflicted children can get the benefit and it can become a national model for CP treatment in future.

All donations are qualified as deduction under section 80g of income tax exemption available under clause 80C (order no. ITBA/EXM/S/80G/2017-18/1004818712(1) Dated 05/07/2017).

**Trishla foundation bank details:**

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| Account name | **Trishla foundation** |
| Account number | 520141001006246 |
| Bank name | Corporation Bank, Georg Town branch, Allahabad |
| IFSC details | CORP0000533 |
| MICR | 211017003 |
| PAN | AACTT6054H |

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