1000 Wheelchairs Project 2015

Sri Lanka

1000 Wheelchairs = 1000 Smiles
Cerebral Palsy and disability in Sri Lanka

Cerebral Palsy (CP) is a condition that affects muscle control and movement. It is usually caused by an injury to the brain before, during or after birth (Scope, 2014). It is one of the most prevalent physical disabilities in childhood - globally almost 17 million people have CP.

Although no scientific research has been done on the prevalence of CP in Sri Lanka, research carried out globally into the prevalence of CP (Gladstone, 2010) suggests that the prevalence in Sri Lanka may be at least 0.2%. This means that there are likely to be more than 40,000 persons in Sri Lanka with this condition (Sunday Times, 2011).

Echoing this need for further research into CP in Sri Lanka, there is also a clear need to boost awareness and understanding of CP, as well as the medical capacity and funding needed to treat the condition. There are, as yet, no specialized surgeries like SEMLARASS, OSSCS in Sri Lanka to prevent or correct deformities for those with CP. And there are very few parents or teachers who are trained in taking proper care of children with CP.

Moreover, Sri Lankan census data underlines the extent to which families with disabled children need financial help; nearly three-quarters of disabled Sri Lankans are dependent on their families for support to survive (ESCAT 2014). This highlights the need for vocational training for young people and adults with CP and disabilities who dream of a life in which they are financially independent.

Cerebral Palsy Lanka Foundation (CPLF)

The CPLF is a non-profit organization set up primarily to assist persons affected by CP, and to support their families. CPLF is the first and the only organization in Sri Lanka established specifically for people with CP. The foundation’s creation was inspired by the clear need to help those with CP in Sri Lanka.

CPLF aims on becoming a centre of excellence which provides world class treatment, services and programmes supporting those with CP, their carers and other stakeholders. The foundation also aims to raise awareness, to build long-term capacity and educate the public and other stakeholder groups on CP and other disabilities.

The Dream Center is the resource and the rehabilitation center of CPLF established to provide educational and therapeutic services (Physio, Occupational and Speech therapy) for the children with Cerebral Palsy and other associated movement disorders. There are three centers in Colombo (Wattala, Moratuwa and Battaramulla) and the vision of CPLF is to start at least one such center in each district of Sri Lanka.

www.cplanka.lk or www.cplanka.org
**Wheels for Wheels Foundation**

An initiative of the charity Wheels for Wheels, its ultimate goal is to donate 40,000 wheelchairs to the children with Cerebral Palsy in Sri Lanka. This is an ambitious and daunting target but Wheels for Wheels strongly believes helping alleviate even some of the pain and suffering young cerebral palsy sufferers endure every day is worth all the effort. Wheels For Wheel each years coupled with Partners and Sponsors organizes Around the Pearl, which is a challenging 10 day cycling ride around Sri Lank spanning 1400km with the primary objective of creating awareness about CP and raising funds for the purchase of wheelchairs. To date funds for 1400 wheelchairs have been raised and 1000 wheel chairs distributed across Sri Lanka.

[http://aroundthepearl.lk/](http://aroundthepearl.lk/)

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**MJF Charitable Foundation**

The MJF Charitable Foundation is an approved charity established by Merrill J Fernando with the objective to formalize activities that were close to the heart of the Founder of Dilmah who has been helping people in need throughout his career. In essence having taken Dilmah to the world, the Founder was equally motivated to ensure that the benefits accrued from the success of Dilmah, also flowed through to the plantation worker communities as well as to the rural and under privileged communities at large and the environment. The Foundation was established as a conduit to ensure that these endeavours are fulfilled in an efficient and effective manner.

The core activities of the Foundation focus on early childhood care and development of plantation children, health and nutrition for plantation women and children, educational support, housing and common amenities for plantation workers, holistic development support for under privileged kids through its MJF Kids programme in Colombo, Pallansena, Moratuwa, Siyambalanduwa and Point Pedro, empowering the differently able and children with special needs, livelihood support for rural communities and those affected by was in the north and east, through which the Foundation serves to embody the Founders philosophy of doing business as a matter of human service. It is also a tribute and symbol of appreciation to the millions of Dilmah tea consumers around the world who are stakeholders of the MJF Charitable Foundation.

Funding and support - Around The Pearl (ATP) 2014

Many families in Sri Lanka do not have access to adequate funds to care for children with Cerebral Palsy and as a result, cannot afford to buy wheelchairs for them. A simple wheelchair can provide a sufferer of CP with greater mobility and freedom, enabling them to enjoy a more fulfilling life.

Even though no act of kindness can give absolute relief to these children and their parents, providing mobility by means of a wheelchair for the financially challenged families might go a long way. This might help bring some joy to the lives of these misfortunate kids and families.

The ‘Around the Pearl’ initiative by ‘Wheels for Wheels’ in support of the Cerebral Palsy Lanka Foundation of Sri Lanka was a 1427 km bicycle tour around Sri Lanka conducted by 12 business professionals, as a first step to raise funds for 1000 wheelchairs to aid children with Cerebral Palsy (CP) in Sri Lanka.

The 12 good Samaritans embarked on a 10 day journey from the 10th – 20th of April2014 that has taken them around the entire island, from Colombo to Weligama, Hambantota, Arugam Bay, Passikudah, Nilaveli, Kilinochchi, Point Pedro, Jaffna, Mannar, Puttalam and many more destinations.
The Project

Cerebral palsy permanently affects body movement and muscle coordination, thus wheelchairs remain an important mode of movement for the affected individuals, providing much needed freedom. Children affected by cerebral palsy usually have limited mobility or are completely bed ridden which often leads to various health complications including muscle contractures. Children who do not have wheelchairs find it difficult to live a fulfilling life as they cannot even leave their homes, so they struggle to make friends and find it difficult to fit into a community. This project was initiated to enable the children with Cerebral Palsy to get out of their house bound situation and to encourage their maximal participation in the society.

The special wheelchair donation camps for children with cerebral palsy will also provide an opportunity for parents to seek assistance if they have a child with cerebral palsy or if they suspect that their child may be affected by the disorder.

The Special Paediatric Wheelchair

The wheelchair which was given in this project is a special Paediatric wheelchair with the seat widths of 30 & 35 cms which is not available in Sri Lanka. The seat and the back rest are cushioned. It comes with shoulder and chest harness, waist belts, leg separators, calf cushions and belts. Its easy fold able and comes with hand brakes for the easy use of the carer or parents.

This wheelchair was selected carefully and a sample was brought last year and was used in our Dream center at Wattala for 6 months to see the user friendliness, durability and effectiveness.

In all the wheelchair camps, parents were instructed and trained on how to use these wheelchairs and its accessories correctly & effectively to get the maximum benefits to their children and the proper positioning of their child in the wheelchair and its importance.
Importance and Benefits of proper positioning in a wheelchair

Children with disability must be well positioned in their wheelchair to be comfortable and for their seating to support them correctly. Good wheelchair posture aims to:

- spread pressure evenly to ensure comfort and prevent development of pressure sores or pain
- minimize fatigue
- maximize a child’s functional potential in activities such as: eating, drinking, communicating, playing and driving or propelling their wheelchair
- improve breathing, digestion & circulation
- limit abnormal tone patterns, such as, pushing back into extension
- minimize the development of muscle tightness and other deformities
- find the balance between providing enough support for function while allowing the child to develop their postural muscles.

The Team and the Wheelchair services training

August 27th-31st, 2014 - The Wheelchair Services Training for Physiotherapists in Sri Lanka 2014 was organized by Cerebral Palsy Lanka Foundation (CPLF) in collaboration with The Spastic Society of Tamil Nadu (SPASTN) from 27th – 31st August 2014. This intensive training workshop was held for 5 days at The Neurotrauma unit Auditorium at the National Hospital, Colombo and funded by the World Health Organization (WHO) in Sri Lanka. 36 Physiotherapists from almost all districts of Sri Lanka participated in this workshop. Theses trained Physiotherapists volunteered in the wheelchair camps to identify, assess and prescribe wheelchairs for the children.
Identification, Assessment and Selection

The families of children with Cerebral Palsy and other physical disabilities were informed with the help of the Social Services Department. The local print media was very helpful in making the public aware of our wheelchair camps by carrying the article and flyer with the details about this project.

The participants in these camps were registered and their medical records and other details were recorded in the registration forms. Each participant was assessed carefully by our team of Physiotherapists and the selection for the wheelchair prescription was made carefully with the following considerations:

- User’s age, size, weight
- User’s disability and prognosis
- User’s functional ability
- Mobility needs and requirements
- GMFCS scoring
- Socio economic and family background
- Living environment and accessibility

The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement with particular emphasis on sitting (truncal control) and walking. It can be categorised into 5 different levels. Distinctions between levels of motor function are based on functional limitations, the need for assistive technology, including mobility devices (such as walkers, crutches, and canes) and wheeled mobility, and to much lesser extent quality of movement. The children with GMFCS scoring of 4 & 5 were considered for the wheelchair prescription in this program.

Each wheelchair donated has a registration number to identify the user, user’s location and for future follow ups.
Free Special Wheelchairs Donation Camp for children with Cerebral Palsy

Does your child have delay / difficulty in sitting or standing or walking?
Does your child have delay or difficulty in speech?
It may be Cerebral Palsy!

To help your child, Please register with us or visit one of the following district wheelchair camps

<table>
<thead>
<tr>
<th>District</th>
<th>Date</th>
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<tbody>
<tr>
<td>Ambalantota</td>
<td>15.02.2013</td>
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<tr>
<td>Anuradhapura</td>
<td>22.02.2013</td>
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<tr>
<td>Moneragala</td>
<td>01.03.2013</td>
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<tr>
<td>Jaffna</td>
<td>08.03.2013</td>
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<tr>
<td>Kandy</td>
<td>15.03.2013</td>
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<tr>
<td>Ratnapura</td>
<td>22.03.2013</td>
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<tr>
<td>Kurunegala</td>
<td>29.03.2013</td>
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<tr>
<td>Galle</td>
<td>09.04.2013</td>
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<tr>
<td>Batticaloa</td>
<td>15.04.2013</td>
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<tr>
<td>Colombo</td>
<td>19.04.2013</td>
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For more information visit our website www.cplanka.org / www.cplanka.lk
Or email us on info@cplanka.org
Or send your details by SMS to 077554328, 0717777355
Ambalantota Camp - 15th February 2015

Venue - MJF Sithijaya centre, Ambalantota (Hambantota)

Total no. of participants - 79
Total no. of wheelchairs given - 54
Registered for future program - 14
Referred for adult wheelchair - 11
Anuradhapura camp - 22nd February 2015
Venue - Yowun Nikethanaye, Anuradhapura

Total no. of participants - 47
Total no. of wheelchairs given - 25
Registered for future program - 17
Referred for adult wheelchair - 5
Moneragala Camp - 1st March 2015

Venue - Subagya School for Visually and Hearing Impaired, Kumbakana, Monaragala

Total no. of participants - 49
Total no. of wheelchairs given - 30
Registered for future program - 12
Referred for adult wheelchair - 7
Jaffna camp - 8th March 2015

Venue - Jaffna Jaipur Centre for Disability Rehabilitation (JJCDR)
Jaffna

Total no. of participants - 248
Total no. of wheelchairs given - 150
Registered for future program - 71
Referred for adult wheelchair - 27
Kandy camp - 15<sup>th</sup> March 2015

Venue - Centre for Handicapped (CFH), Digana, Kandy

Total no. of participants - 133
Total no. of wheelchairs given - 112
Registered for future program - 12
Referred for adult wheelchair - 9
Ratnapura camp - 22\textsuperscript{nd} March 2015

Venue - District Secretariat Hall, New Town, Rathnapura

Total no. of participants - 83
Total no. of wheelchairs given - 66
Registered for future program - 11
Referred for adult wheelchair - 6
Kurunegala camp - 29th March 2015

Venue - Department of Social Services Hall, Kachcheri road, Kurunegala

Total no. of participants - 144
Total no. of wheelchairs given - 108
Registered for future program - 19
Referred for adult wheelchair - 17
Galle camp - 9th April 2015
Venue - International Buddhist Center, Galle

Total no. of participants - 98
Total no. of wheelchairs given - 77
Registered for future program - 13
Referred for adult wheelchair - 8
Batticaloa camp - 12th April 2015

Venue - Charles Hall, Bishop's house, Batticaloa

Total no. of participants - 180
Total no. of wheelchairs given - 140
Registered for future program - 27
Referred for adult wheelchair - 13
Colombo South (Moratuwa) camp - 19th April 2015

Venue - MJF Centre for Dignified Empowerment, Moratuwa

Total no. of participants - 86
Total no. of wheelchairs given - 61
Registered for future program - 25
Referred for adult wheelchair -
Wellawaya camp - 10th May 2015

Venue - Mahinda Rajapakse Auditorium, Wellawaya

Total no. of participants - 69
Total no. of wheelchairs given - 54
Registered for future program - 15
Referred for adult wheelchair -
<table>
<thead>
<tr>
<th>Colombo North (Wattala) camp</th>
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<tbody>
<tr>
<td><strong>Venue</strong></td>
<td>-</td>
<td><strong>The Dream Center for Children with Cerebral Palsy, Wattala</strong></td>
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| Total no. of participants   | - | 70 |
| Total no. of wheelchairs given | - | 70 |
| Registered for future program | - | |
| Referred for adult wheelchair | - | |
Nuweraliya (Waltrim Estate) camp - 14th June 2015

Venue - Waltrim Estate, Resource center

Total no. of participants - 38
Total no. of wheelchairs given - 25
Registered for future program - 13
Referred for adult wheelchair -
The Sri Lanka Dental Association (SLDA) is the national and the parent body of the dental profession in Sri Lanka. Dental Screening camps were organized with the help of SLDA to help these children who participated in the wheelchair camps and many children with dental and oral hygiene problems were identified and treated. Some children were referred for further treatments and parents were instructed on oral hygiene.  www.slda.lk
VISION 2020 is the global initiative for the elimination of avoidable blindness, launched in 1999, jointly by the World Health Organization (WHO) and the International Agency for the Prevention of Blindness (IAPB) with an international membership of NGOs, professional associations, eye care institutions and corporations. Eye and Vision screening for the children was done with the help of Vision 2020 and many children were referred for further screening and treatment.
Children with cerebral palsy commonly have feeding disorders and swallowing problems (dysphagia) that in many instances place them at risk for aspiration with oral feeding, with potential pulmonary and other life threatening consequences. They also commonly have reduced nutrition/hydration status and prolonged stressful meal times. Parents and carers were trained on proper positioning, correct feeding techniques and appropriate types of foods.
Impact and Feedback
Inclusion and Participation in the Society

A family trip

Participating in a dance program

At the park

A school trip