## **MILESTONES**

## **CEREBRAL PALSY LANKA FOUNDATION**

# **2014 – SRI LANKA**

**PREPARED BY** 

### **Gopi Kitnasamy** BSc MCSP(UK) MIMDTP(UK)

**Chartered Physiotherapist** Certified Paediatric Bobath Therapist Founder / Director



සෙරිඞ්රල් පොල්සි ලංකා ෆවුන්ඩේෂන් செரிபரல் பால்சி லங்கா பௌண்டேசன் Cerebral Palsy Lanka Foundation



Center for Children with Cerebral Palsy

#### Introduction

Cerebral Palsy (CP) is the term used for a group of non progressive disorders of movement and posture caused by abnormal development of, or damage to, motor control centers of the brain. CP is caused by events before, during, or after birth. It is the **most common physical disability in childhood.** 

Despite substantial improvements in obstetric and neonatal care, the worldwide prevalence of cerebral palsy has **remained stable at 2 to 3 per 1,000 live births for more than 40 years.** Cerebral Palsy remains a significant health problem. The number of people affected by Cerebral Palsy has increased over time. Almost 17 million people around the world have Cerebral Palsy and there are nearly 1.5 – 2 million children and adults with Cerebral Palsy in United States (United Cerebral Palsy (UCP) Foundation). 10,000 babies and infants are diagnosed with Cerebral Palsy annually in United States.

In Sri Lanka, there are an estimated number of 40,000 children and adults with Cerebral Palsy. There are many undetected cases.

**Cerebral Palsy Lanka Foundation** (CPLF) is the first and the only organization for children with Cerebral Palsy in Sri Lanka. It was started with an objective to provide educational and therapeutic services for children with Cerebral Palsy and associated movement disorders. It was started in 6<sup>th</sup> October 2011 at 7 Captain Kelum Rajapakse Mawatha, Wattala.

"The Dream" center is the resource center of Cerebral Palsy Lanka Foundation (CPLF) started with the aim to provide special education and therapy (Physio, Speech and Occupational) for the children with Cerebral Palsy in Sri Lanka. At present, we have two centers one in Wattala and other one in Moratuwa and will soon start the third center at Nugegoda. The mission of CPLF is to start atleast one such center in every district of Sri Lanka to help these children in their localities.

Cerebral Palsy Helpline : 0714342247 or 0777554328

email: gopi291975@yahoo.com

website : www.cplanka.org

**6<sup>th</sup> October 2011** - **Opening Ceremony** of Cerebral Palsy Lanka Foundation (CPLF) at Wattala, which is the first and the only organization for children with Cerebral Palsy and their families in Sri Lanka. It was officially opened by **Mr. Senarath Attanayake**, currently a member of the Uva Provincial Council, Sri Lanka and was the Minister of Agriculture, Irrigation, Livestock, Land and Forestry of the Uva Provincial Council from 2000-2005 as well as the acting Chief Minister for a brief period during this tenure. **Mr. Attanayake** is the first wheelchair user in Sri Lanka to become a politician and lawyer and the only wheelchair user to hold a ministerial portfolio.



**10<sup>th</sup> October 2011** - **The Dream** Center for children with Cerebral Palsy, which is the resource center of CPLF started functioning at Wattala (Colombo North branch). It is first such center which is exclusively for children with Cerebral Palsy.



28<sup>th</sup> October 2011 - Workshop for Parents with CP children organised by CPLF at Lady Ridegway
Hospital, Colombo was conducted by Dr. Taral Nagda, Paediatric Orthopedic Surgeon from Mumbai and Dr. Sunil
Wijesinghe, Orthopedic Surgeon from Lady Ridegway Hospital, Colombo.



26th January 2012-Speech Therapy and Dysphagia Management workshop was conducted by Ms.Sagasaki, Senior Pediatric Bobath (Speech) Therapist from Japan, for parents and Speech therapy students from<br/>Kelaniya University.



January – April 2012 - Speech therapy students from Kelaniya University attended The Dream Center, Wattala for their clinical placements.



8<sup>th</sup> March 2012 - Launching ceremony of Cerebral Palsy Information Services in Mobitel Liyasara by Cerebral Palsy Lanka Foundation in collaboration with Sri Lanka Telecom Mobitel at the Temple Trees by the Madame Shiranthi Rajapakse, the First Lady of Sri Lanka.



**8<sup>th</sup> May 2012** - The second branch and the South Colombo branch of **The Dream** center was officially opened by **Mr. Merrill J. Fernando** founder of Dilmah Tea and MJF Foundation, at Moratuwa which was started in partnership with MJF Foundation to help the Cerebral Palsy children in Colombo South area.



28<sup>th</sup> May – 2<sup>nd</sup> June 2012- The first ever "National Cerebral Palsy Awareness week" was organized by the CPLF and launching ceremony was held at the Sri Lanka Foundation Institute. An awareness video about Cerebral Palsy created by Leo Brunett, was released to the public and Media by Dr. F.R. Mehta, Country Director of the World Health Organization in Sri Lanka and Mr. Jung Sun Hong, Senior International Paediatric Bobath instructor.

The first awareness and assessment camp was organized and conducted at **Excel world, Colombo** by CPLF with the help of **Recoup, Bangalore, India.** Following which the awareness and assessment camp in **6 more districts** (Tangalle, Galle- 2 camps at 2 different centers, Kandy, Anuradhapura, Jaffna, Killinochchi) were conducted by CPLF and nearly 600 children with their parents participated and benefitted. This project was supported by the **World Health Organization** in Sri Lanka.



Assessment and awareness camp at Excel World, Colombo on 28<sup>th</sup> May 2012



Assessment and awareness camp at Navajeevana Center, Tangalle on 29<sup>th</sup> May 2012 (Morning)



Assessment and awareness camp at Mrs. Madhusani's center, Galle on 29<sup>th</sup> May 2012 (Evening)



Assessment and awareness camp at Martin Wickramsinghe College, Habaraduwa, Galle on 30<sup>th</sup> May



Assessment and awareness camp at Physiotherapy Department, Kandy General Hospital on 31st May 2012



Assessment and awareness camp at Professorial Unit, Anuradhapura General Hospital on 1st June 2012



Assessment and awareness camp at Nursing School Hall, Jaffna on 2nd June 2012



Assessment and awareness camp at on Karuna Nilayam, Killinochchi 3rd June 2012

CPLF in collaboration with the **Sri Lanka Society of Physiotherapy** organized the **Asian Paediatric Bobath Therapy course** and was supported and funded by the **World Health Organization** in Sri Lanka, Introduction course and workshop on Paediatric Bobath Therapy at the Banquet Hall, Excel World, Colombo from 29<sup>th</sup> May – 2<sup>nd</sup> June 2012. This workshop was conducted by **Mr. Jung Sun Hong**, Senior International Paediatric Bobath instructor and his team from South Korea. Nearly 38 Physiotherapists from Sri Lanka and 2 Physiotherapists from India participated in this workshop and were trained to assess and treat children with Cerebral Palsy using Bobath Concept.



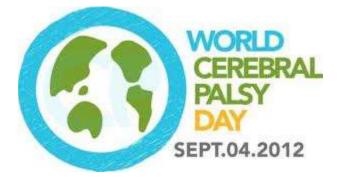
**4<sup>th</sup> June 2012** - On the request of the parents of children with Cerebral Palsy, CPLF organized a special assessment camp with the help of **Mr. Jung Sun Hong**, Senior International Paediatric Bobath instructor and his team from South Korea and the Physiotherapists from **Recoup, Bangalore**, India at The Dream Center, Wattala.



**2<sup>nd</sup> July 2012** - The **second (The Dream**) center, started functioning successfully at Moratuwa with 10 Cerebral Palsy children . Now (January 2013), there are 35 children with Cerebral Palsy who are attending The Dream center (Moratuwa) for special education and therapeutic services on a regular basis.

**1**<sup>st</sup> **September 2012** - A **Cerebral Palsy Awareness video** was released at the **Lanka Faces** Special Night at Nelum Pokuna theatre, Colombo with the help of Lanka Faces.

**4<sup>th</sup> September 2012** - CPLF represented children and persons affected by Cerebral Palsy in Sri Lanka in the first ever **World Cerebral Palsy Day** organized by **Cerebral Palsy Alliance, Australia** and participated by organizations from 35 countries.



25<sup>th</sup> October 2012 - 5 times World Rowing Champion and 2012 Olympic Gold medallist, Mr. Mahe Drysdale visited The Dream center at Wattala, along with Dr. F.R. Mehta, Country Director of the World Health Organization in Sri Lanka, Mr. Senaka Silva, Consul for New Zealand in Sri Lanka and Mr. Senarath Attanayake, which was organized by the T-Sips, Expolanka Teas (Pvt.) Ltd.





On the **25<sup>th</sup> October** 2012 evening, at an event at Galle Face hotel, the **winning Jersey** of **Mr. Mahe Drysdale** was auctioned by him and raised **2.35 million** Sri Lankan Rupees, which was donated to the CPLF. An **awareness video** about Cerebral Palsy and The Dream center, which was created by **5<sup>th</sup> Elephant team** was also released on the same day. This event and the auction was organized by the **T-Sips, Expolanka Teas (Pvt.) Ltd.** 



2<sup>nd</sup> December 2012 - The students from "The Dream" Center for children with Cerebral Palsy, Wattala & Moratuwa particpated in the Dream Cricket. This wonderful event was organized by Don Bradman Foundation, Australia and The Rotary Club of Colombo West. There were 110 participants with special needs from all over the country. It was organized to celebrate the "World Different Ability (Disability) Day", which was on the 3rd December.



**26<sup>th</sup> January 2013** - This year, it was the 20th Anniversary of Kala Pola which is the Sri Lanka's highly popular open-air art exhibition cum fair. Thanks to George Keyt Foundation and John Keells Foundation for helping these wonderful artists in Sri Lanka by organizing this great event. We are very grateful that on the request of Cerebral Palsy Lanka Foundation(CPLF), they gave this wonderful opportunity to exhibit the artwork done by children with special needs and underprivileged children. Children from "The Dream" Center for children with Cerebral Palsy (Resource center of CPLF), MJF Foundation(MJF) and Nobuchi Children's Home exhibited their paintings. At this event "Mouth and Foot Painting Artists Group of Sri Lanka" which is a subsidiary of CPLF was started. Ms.Dulanjali Ariyatilaka is heading the group and Ms. Rashmi Gunawardene will be the first member of it. They also exhibited their paintings

done with their feet at the Kala Pola 2013. More than 300 artists from Sri Lanka participated in this event and we are proud to say that our 12 young specially talented artists (5 from CPLF, 5 from MJF and Dulanjali and Rashmi) were also part of it. Our special thanks to Cinnamon Grand, Public Relations team for organizing this event.



10<sup>th</sup> February 2013 - With God's blessings and help from kind hearted people, Cerebral Palsy Lanka
Foundation (CPLF) was able to raise funds for 10 wheelchairs for the children and adults at Sister Rita's Marcsri home, Kalutara. This is a wonderful place, many say it as an orphanage but this is a great home and family for these kids! These kids have different types of physical disabilities (I remember the quote "Disability is the Inability to see Ability" but one thing in common, the happiness and courage! We are happy that we met Dulanjali
Ariyatilaka (head of the "Mouth and Foot Painting Artists Group of Sri Lanka" a subsidiary of CPLF), it is because of her, we were met these wonderful kids! These wheelchairs will be useful for them to go around, out and to school.



17<sup>th</sup>-19<sup>th</sup> March 2013 - Our Cerebral Palsy Awareness video titled "Whistle Story" won two awards at the ADFEST 2013, held at Pattaya, Thailand. This video was created by the director Mr. Subhash Pinnapola and his team from Leo Burnett, Sri Lanka. This video was was released to the public and Media by Dr. F.R. Mehta, Country Director of the World Health Organization in Sri Lanka and Mr. Jung Sun Hong, Senior International Paediatric Bobath instructor on the launching ceremony of the "National Cerebral Palsy Awareness week" which was organized by the CPLF and was held at the Sri Lanka Foundation Institute on the 28<sup>th</sup> May 2012.



**18<sup>th</sup> June 2013** - Cerebral Palsy Lanka Foundation has got the copyrights and the translation rights for both Sinhala and Tamil versions of "You and Your Disabled Child" which is a practical guide for all parents with a special child. The first copy of the book was handed over to **Madame Shiranthi Rajapakse**, First Lady of Democratic Socialist Republic of Sri Lanka by Master Danush Gopi at the President's house.





**30<sup>th</sup> August- 2<sup>nd</sup> September 2013**- Awareness and assessment camps were organized and conducted by CPLF for the second time with the help of **Recoup, Bangalore, India.** The programs were conducted in **three districts** (Kandy, Killinochchi, Colombo- 2 camps at Moratuwa and Wattala) Killinochchi) and nearly 100 children with their parents participated and benefitted.



Assessment and awareness camp at Kandy on 30<sup>th</sup> August 2013



Assessment and awareness camp at Killinochchi on y 31<sup>st</sup> August 2013



Assessment and awareness camp at Moratuwa, 1<sup>st</sup> September 2013



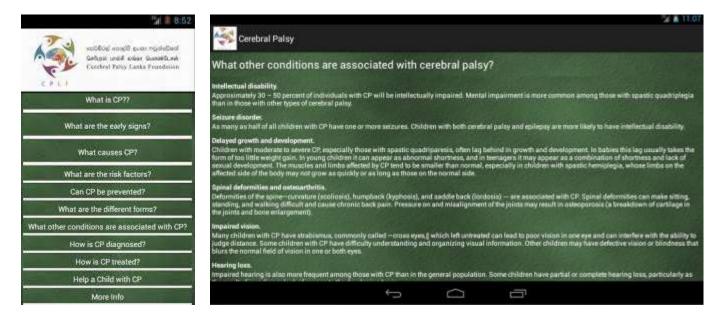
Assessment and awareness camp at Wattala, 2<sup>nd</sup> September 2013

2<sup>nd</sup> October 2013 - CPLF launched the Cerebral Palsy Information Services in all three local languages (Sinhala, Tamil & English) created by Cerebral Palsy Lanka Foundation and supported by Mobitel! We launched this service via Mobitel, on the World Cerebral Palsy Day and sent a sms to Celebrate "World Cerebral Palsy Day" and create awareness about Cerebral Palsy.





**4<sup>th</sup> October 2013** - The World's first Android (mobile & Tablet) App for Cerebral Palsy was created and launched by Cerebral Palsy Lanka Foundation. It's a completely free App, created to help the users with information about Cerebral Palsy which will connect user to various organizations working for children with Cerebral Palsy around the world.



**6**<sup>th</sup> **November 2013** - First Wheelchair Swing and Inclusive Play Area at "The Dream" Center for children with Cerebral Palsy, Wattala was started by CPLF.



**20<sup>th</sup> - 24<sup>th</sup> January 2014 –** CPLF organized a workshop Bobath Paediatric Approach by Mr.Hong Jung Sun, PT, MPH, Senior International Bobath Paediatric Instructor for the therapists from India and Sri Lanka. This was conducted at the Cerebral Palsy Conference: Recent advances in Functional Rehabilitation of Cerebral Palsy, Bangalore in collaboration with the Recoup hospital.



23<sup>rd</sup> February 2014 - The students from "The Dream" Center for children with Cerebral Palsy, Wattala & Moratuwa particpated in the Dream Cricket. This wonderful event was organized by Don Bradman Foundation, Australia and The Rotary Club of Colombo West. There were 110 participants with special needs from all over the country.



2<sup>nd</sup> April 2014 – A wheelchair swing was installed at the Lady Ridgeway Hospital for Children and the Viharamahadevi park near Townhall to make it as the first Inclusive public park in Sri Lanka. This project was funded by the **World Health Organization** in Sri Lanka. This **"Wheelchair Swing**" which is an innovative and worthy initiative by CPLF, was made using the local resources available in Sri Lanka. CPLF is taking initiatives to install this swing in all the public parks in Sri Lanka.





5<sup>th</sup> April 2014 - It was a wonderful day and a great surprise for the kids and the staffs at The Dream center, seeing Mr. & Mrs. Muttiah Muralidharan. The Legend Cricketer and his wife visited The Dream Center at Wattala. The kids had a great time with them!



10<sup>th</sup> – 20<sup>th</sup> April 2014 – "Around the Pearl" a joint initiative by CPLF and Wheels for Wheels to fund raise for 1000 wheelchairs which will be donated to the children with Cerebral Palsy in Sri Lanka. These are special wheelchairs which will be donated to the poor families with these children in Sri Lanka. This will be an ongoing project to fund raise more wheelchairs to be donated to children and adults with Cerebral Palsy in Sri Lanka.



**27**<sup>th</sup> **May 2014** - The IPhone version of the World's first App for Cerebral Palsy was launched by Cerebral Palsy Lanka Foundation. It's a completely free App, created to help the users with information about Cerebral Palsy which will connect user to various organizations working for children with Cerebral Palsy around the world.

iPod 🗟	11:31 AM @		iPod 🗟	11:31 AM	•	
	Cerebral Palsy Questionr	naire	K Back	Questionnaire		
CPL	පෙට්ඩ්රල් පොල්සි ලංකා පවුන්වේද ලෝධාන පාන්ම නත්සා Guaraide. Cerebral Palsy Lanka Foundati F	reit	Was born pr	ematurely (before 30 w	eeks)	
	What is Cerebral Palsy?		Was born ve	ry low weight (less that	n 1500 gms)	
N	What are the early signs?		Yes			
W	hat causes cerebral palsy?		No No			
V	What are the risk factors?		Was delivere delivery	ed in Breech (legs first)	or difficult	
Can	cerebral palsy be prevented?		Yes			
Wi	hat are the different forms?		No No			
Other	Other conditions associated with CP		Born with severe Jaundice or developed after delivery			
How	How is cerebral palsy diagnosed?		Yes			
Ho	w is cerebral palsy treated?		NO.			

**22<sup>nd</sup> June 2014** – A workshop on Positioning and Hand Function for children with CP was organized by Cerebral Palsy Lanka Foundation for the therapists and the teachers of The Dream Center, Wattala. The resource person for this workshop was **Ms. Shamini Logannathan,** an Occupational Therapist from Singapore, who was on International clinical placement from Coventry university, United Kingdom.



**6th August 2014** - Art & Craft Exhibition 2014, an exhibition of work done by the students of The Dream Center for Children with Cerebral Palsy was held at Wattala. A felicitation program for the heroes of "Around the Pearl" project was also organized by CPLF on the same day. The theme for 2014 exhibition was "With A Little Help, We Can Do It!"





**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 Sri Lanka Society of Physiotherapy, Government Physiotherapists' Association in Sri Lanka and 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 in Sri Lanka.

Four wheelchair services training experts from SPASTN functioned as resource persons for this workshop and 36 Physiotherapists from almost all districts of Sri Lanka participated in this workshop. At the end of this 5 days' workshop, Wheelchair Services Sri Lanka group was formed and Physiotherapists representing each districts in Sri Lanka joined the group as representatives to co-ordinate future activities.



**4th & 5th September 2014** - Sensory Integration Therapy workshop was organized by Cerebral Palsy Lanka Foundation for the therapists and the teachers of both Wattala and Moratuwa centers. It was held at The Dream Center, Wattala. The resource person for this 2 days workshop was **Mr. Poovazhagan Ulaganathan**, a Physiotherapist who is certified in Neuro Developmental Therapy and Sensory Integration Therapy (USA)



12<sup>th</sup> September 2014 – Cerebral Palsy Lanka Foundation started the Wheelchair Services in Sri Lanka with the first camp at a Special unit in a Primary School in Laxapana, Hatton. It was a wonderful experience and we met many parents and children with special needs. We gave them few Paediatric wheelchairs and trained the parents on how to use it and take care of their children in the wheelchair.



**20th September 2014** - **Dr. Deepak Sharan**, Paediatric Orthopedic Surgeon and Medical Director of Recoup Hospital, Bangalore, visited The Dream Center for Children with Cerebral Palsy at Wattala. The parents of children with Cerebral Palsy had the opportunity to consult him and get his advice. It was a great opportunity for them.



**21<sup>st</sup> September 2014** - A workshop on "Recent Advances in Rehabilitation of Cerebral Palsy" was organized by Cerebral Palsy Lanka Foundation for the Physiotherapists. It was held at The Dream Center, Wattala. The resource person for this workshop was **Mr. Mathankumar Mohandoss,** a Senior Physiotherapist from Recoup Hospital, Bangalore.



**29<sup>th</sup> September 2014** -**Dr. F.R. Mehta** (WHO Country Representative for Sri Lanka) with his family visited The Dream Center for Children with Cerebral Palsy at Wattala. We celebrated the "World Cerebral Palsy Day". It was a wonderful event!



**29<sup>th</sup> September 2014 – First Inclusive Park in Sri Lanka** was launched by Cerebral Palsy Lanka Foundation with the support of World Health Organization (WHO), Urban Development Authority (UDA) and Colombo Municipal Council (CMC). This swing was designed by us and made in Sri Lanka. This will be the start and will have more inclusive parks in Sri Lanka. This was launched to mark the "World Cerebral Palsy Day".



**28th October 2014 - Dr. Jayanth Sampath**, Consultant Pediatric Orthopedic Surgeon from BIMRA (Bangalore Institute of Movement Research and Analysis) Bangalore, India, visited The Dream Center for Children with Cerebral Palsy at Wattala. The parents of children with Cerebral Palsy had the opportunity to consult him and get his advice. It was a great opportunity for them.



18<sup>th</sup> November 2014 - Miss World - Sri Lanka Ms. Chulakshi Ranathunga's visit to The Dream Center for Children with Cerebral Palsy, Wattala. She is our ambassador for Cerebral Palsy in 2014. Thank you Chulakshi for helping to create awareness about Cerebral Palsy in Sri Lanka!



**3**<sup>rd</sup> **December 2014** - The Dream Concert and the World Disability Day Celebrations was organized by the Cerebral Palsy Lanka Foundation at The Dream Center, Wattala. **Mr. Subinay Nandy**, United Nations Representative for Sri Lanka was the Chief Guest and **Mr. Senarath Attanayake**, UVA Provincial Council Member was the Guest of honor. We were honored and privileged by the inspirational presence of them along with Mrs. Nandy and Mrs. Attanayake. The performances of the students of The Dream were excellent. It was a fantastic show! A great way to celebrate the World Disability Day!





**3**<sup>rd</sup> **December 2014 -** 20 Wheelchairs were donated to children and adults with disabilities on the World Disability Day. This was made possible by the kind sponsor from the Rotary Club of Colombo Down Town and the efforts of **Mr. Yasas Hewage**, President of the club.

There was a girl who desperately needed a wheelchair and she came all the way from Hatton (119KM oneway) in a 3 wheeler to get a free wheelchair. There are thousands like her in Sri Lanka who are in need of a wheelchair for their mobility and can't afford to buy one. We are trying our best to help all of them.



**21<sup>st</sup> December 2014** - Appropriate Paper Based Technology (APT) Workshop was organized for the first time in Sri Lanka by CPLF jointly with the University of Kelaniya. This workshop was held as a post "A Voice for All" conference workshop. **Mrs. Nigamaja Hariharan,** Paediatric Physiotherapist was the resource person for this workshop. Therapists, Teachers and parents from many districts of Sri Lanka participated and got trained in APT.

