

## Karnataka Paediatric Journal



**Editorial** 

## Uniquely cerebral palsy – World cerebral palsy day

Bhaskar Shenoy<sup>1</sup>

<sup>1</sup>Department of Pediatrics, Manipal Hospital, Bengaluru, Karnataka, India.

## \*Corresponding author:

Bhaskar Shenoy, Department of Pediatrics, Manipal Hospital, Bengaluru, Karnataka, India.

bshenoy@gmail.com

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World Cerebral Palsy (CP) day, celebrated annually on October 6, is a global initiative aimed at raising awareness about CP and advocating for the rights of those affected by the condition. Established to highlight the challenges faced by the estimated 1.8 crore people living with CP worldwide, the day serves as a platform for individuals, families, and organisations to share experiences and promote understanding. There are more than 17 million people across the world living with CP. Another 350 million people are closely connected to a child or adult with CP. Nearly 15-20% of physically disabled children are affected by CP. In India, the estimated incidence is around 3/1000 live births.

Every year, October 6 is an opportunity to come together and celebrate the resilience, diversity, and vibrancy of people with CP. It is also a moment to campaign for meaningful, positive changes to accessibility and inclusion in society and recognize the contributions of family, carers, and allies. In 2024, the global campaign theme for World CP Day is uniquely CP. This theme celebrates the uniqueness and passions of individuals with CP, highlighting their individuality and unique experiences. Every individual with CP is unique, with passions, pursuits, and identities beyond just that of a person with a disability. CP is often misunderstood in the wider community, and we should overcome these stereotypes by celebrating the individuality and personality of the community.

The 2024 campaign theme aims to empower people with CP, family members, and supporters to share stories about their achievements and passions - how CP makes all unique. World CP Day is a global movement that started in 2012. The CP Alliance in 2012 declared October 6 as World CP Day to bring together people with CP, their friends, families, and organisations. It also aims to ensure that children and adults with CP have the same rights, opportunities, and access as everyone else globally. Last year, it reached over 10 million people. It aims to bring together people living with CP, their families, supporters, and organisations from over 100 countries. All with the aim to ensure a future in which children and adults with CP have the same rights, access, and opportunities as anyone else in our society.

CP Day is a social movement. The first World CP Day campaign was called 'Change My World in 1 Min.' The project sought ideas from the global community of people with CP for technologies and products that needed inventing - that had the potential to 'change the world' for people living with CP. In 2012, more than 470 ideas were posted on the World CP Day website. Three ideas were shortlisted, and then the call went out to inventors. A research team from the University of Virginia (USA) won the major prize. They developed a prototype solar-powered wheelchair, which was an idea posted by Alper Sirvan, a man with CP in Turkey. The wheelchair prototype was presented to Alper on World CP Day 2013. In 2015, the campaign evolved into a social

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movement that targets the six key issues that affect people with CP around the world, irrespective of geographical, cultural, and economic differences.

CP is a physical disability that affects movement and posture. Many people with CP have other related vision, hearing, communication, and mobility needs. Its impact can range from a weakness in one hand to almost a complete lack of voluntary movement. As per a 2022 research report, the birth prevalence for pre-/perinatal CP in regions from high-income countries was 1.5/1000 live births and 1.6/1000 live births when post-neonatal CP was included. A majority (82.9%) of the children with CP had spastic CP. More than half (58.9%) of the children with CP could walk independently.

It is a complex disability:

- 1 in 4 children with CP cannot talk
- 1 in 4 cannot walk
- 1 in 2 have an intellectual disability
- 1 in 4 have epilepsy.

Here are five important facts about CP:

- 1. CP is the most common childhood disability, affecting 1 in 345 children
- Approximately 1 million people in America and 18 million worldwide have CP
- Among those with CP, 75% experience chronic pain, and 25% are non-verbal
- CP is not progressive, meaning it does not get worse over
- The five types of CP include spastic, dyskinetic, ataxic, hypotonic, and mixed.

CP is one of the least understood disabilities due to a lack of awareness regarding this condition. The world of CP creates a platform to emphasise awareness with respect to the disease,

diagnosis, and treatment, in addition to addressing the challenges CP patients face.

## PREVENTION OF CP DURING PREGNANCY

prevention during pregnancy is dependent on maintaining good habits and staying healthy. The following are the ways to prevent CP at the time of pregnancy that includes:

- Staying away from exposure to infections or viruses that are known to harm foetal health, such as German Measles, Cytomegalovirus, or Zika
- Getting the necessary vaccinations
- Managing underlying health conditions
- Avoiding alcohol and cigarettes
- Recognising any potential Rh incompatibility between mother and child.

In 2024, the focus will continue to be on inclusion and celebrating the diverse contributions of individuals with CP across various fields. Activities may include awareness campaigns, fundraising events, and educational workshops designed to improve support and services for those living with CP. By fostering community engagement and collaboration, World CP Day aims to create a more inclusive society where individuals with CP can thrive and have equal opportunities. Let us join hands in this noble action.

> Dr. Bhaskar Shenoy, Editor in Chief, Karnataka Pediatric Journal.

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