

# CEREBRAL PALSY ITALIAN NETWORK (ITA NET CP): PROSPECTIVE STUDY ON THE NATURAL HISTORY OF ADAPTIVE FUNCTION

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## BACKGROUND

Cerebral palsy (CP) is the most common cause of physical disability in childhood, affecting 2-2.5 per 1000 live births<sup>1</sup>. CP is defined and classified as a complex disorder limiting movement and affecting posture, but also impairing sensation, perception, cognition and behavior<sup>2</sup>.

Advances in neuroscience have improved our understanding of what causes CP, and led to the development of new multidimensional rehabilitation models in which motor function is considered as a perceptual-motor-cognitive process<sup>3</sup>.

The World Health Organization's International Classification of Functioning, Disability and Health<sup>4</sup> has emphasized the need for family-centered healthcare models and an ecological approach to treatment that strives to assure children with CP and their families a satisfactory quality of life. Central to this approach is the idea that motor symptoms should not be the only object of treatment. Fundamental aspects like manipulating objects and praxies<sup>5</sup>, visual functions, cognitive development<sup>6</sup>, communication, independence in activities of daily living, and quality of life (QoL) should all be considered<sup>7</sup>.

## AIM OF THE STUDY

The aim of this prospective multicenter study is the standardized collection of data relating to the main adaptive functions using a carefully-chosen set of instruments to assess all adaptive functions (gross motor, manual, perceptive, sensory, cognitive, emotional and communicational-relational) and also quality of life, in a large series of Italian children with cerebral palsy.

## INCLUSION CRITERIA

- Diagnosis and classification of cerebral palsy (Rosenbaum 2006)
- Age at first assessment between 2 and 10 years
- Brain MRI performed after 2 years of age and classified according to SCPE<sup>8</sup>
- Informed consent obtained

## MATERIALS AND METHODS

This study has a prospective, multi-center observational design, children (2 to 10 years old) with cerebral palsy were recruited from several centers forming part of an Italian network. The prospective protocol provides for the assessment of gross motor, manual, visual and cognitive functioning, emotional-behavioral aspects, autonomy, and quality of life (Figure 1).

| FUNCTIONAL CLASSIFICATION SYSTEMS                   | VISUAL ASSESSMENT                                                     |
|-----------------------------------------------------|-----------------------------------------------------------------------|
| Gross Motor Function Classification System (GMFCS)  | Oculomotor Abilities and Extrinsic Ocular Motility                    |
| Manual Ability Classification System (MACS)         | Visual Acuity                                                         |
| Visual Function Classification System (VFCS)        | Visual Field                                                          |
| Communication Function Classification System (CFCS) | Visual Motor Integration Test                                         |
| FUNCTIONAL ASSESSMENT OF THE UPPER LIMB             | COGNITIVE ASSESSMENT                                                  |
| Melbourne Assessment Scale II                       | Griffiths III                                                         |
| Besta Scale                                         | WISC IV (Wechsler Intelligence Scale for Children)                    |
| AHA Scale                                           | QUESTIONNAIRES                                                        |
| MOTOR ASSESSMENT                                    | Child Behavior Checklist (CBCL)                                       |
| Gross Motor Function Measure (GMFM 66)              | Pediatric Evaluation of Disability Inventory Adaptive Test (PEDI-cat) |
|                                                     | PEDSQL                                                                |

Fig.1 : Protocol of study

The protocol was applied to children with CP in an age range starting from their second year of life up to 10 years old, at the baseline (T0), after 12 months (T1), and finally after 24 months (T2).



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## RESULTS

Description of clinical variables detected through data analysis (Figure 2):

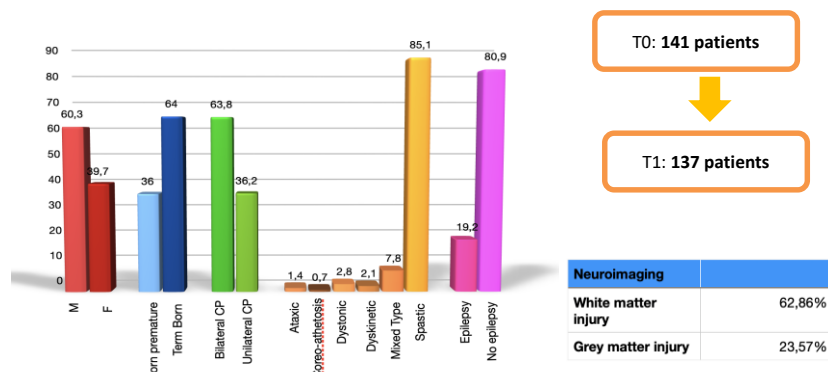


Fig. 2: Description of clinical variables of the sample

Based on a sample of 137 children with CP, at T1 (12 months from baseline) we found:

- Level of function:** GMFCS (74,18%) MACS (89%), VFCS (99,2%), CFCS (92%) showed stability.
- Outcome measures:** GMFM-66 showed significant improvement (median: +2.2; IQR: 0-7.3) in the first 5 years of age (p < 0.0001).

- Behavior:** Internalised aspects prevailed in the CBCL questionnaire which seemed to correlate at an early age with severity levels. In the evolution to T1 they increased in the mildest form.
- Cognitive assessment:** from T0 to T1 we found stable General Developmental Quotient in children <6 years at Griffiths III (role of gross and fine motor skills?), while the evolution in older children, investigated using WISC IV scale highlights, a statistically significant improvement despite persisting correlation with manipulative- praxic aspect (Figure 3).

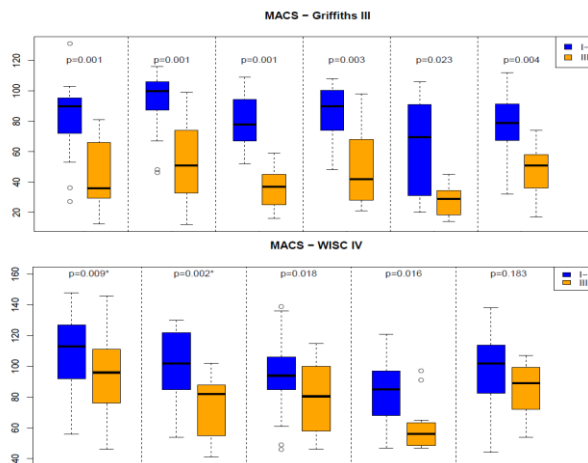


Fig. 3: The graphs show the relationship between cognitive aspects and MACS divided according to the level of severity.

## REFERENCES

- Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson B. (2007) A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol 109 (Suppl 109):8-14.
- Van Naarden BK, Doernberg N, Schieve L, Christensen D, Goodman A, Yeargin-Allsopp M. (2016) Birth prevalence of cerebral palsy: a population-based study. Pediatrics. 137.
- Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson B. (2007) A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol 109 (Suppl 109):8-14
- World Health Organization Classification of Functioning, Disability and Health. Children and youth version. (2007) Geneva: WHO, 200
- Hoare B, Ditchfield M, Thorley M, Wallen M, Bracken J, Harvey A, Elliott C, Novak I, Crichton A. (2018). Cognition and bimanual performance in children with unilateral cerebral palsy: protocol for a multicentre, cross-sectional study. BMC Neurol.18 (1):63.
- Stadsklev K. (2020) Cognitive functioning in children with cerebral. Dev Med Child Neurol 62: 283-289
- Rosenbaum, P. (2020). How do we know if interventions in developmental disability are effective? Dev. Med. Child Neurol. 62: 1344-1344.
- Himmelmann K, Horber V, De La Cruz J, Horridge K, Mejaski-Bosnjak V, Hollody K, Krägeloh-Mann I, SCPE Working Group. (2017). MRI classification system (MRICS) for children with cerebral palsy: development, reliability, and recommendations. Dev Med Child Neurol 59(1), 57-64.

## CONCLUSIONS

Our work represents the first multicentric study in the Italian CP population focusing on the evolution of adaptive functions through a multidimensional and shared protocol as a fundamental prerequisite for planning and defining rehabilitation programs.

The project will contribute to increasing knowledge of the natural history of Cerebral Palsy in Italy, which is a prerequisite for the definition of integrated treatment strategies based on the role of the different adaptive functions and their evolution over time.

It is in fact from the functional profile that an individualized rehabilitation is derived, which will allow the achievement of a better quality of life for the child and his/her family. This could contribute to the development of appropriate health and social policies.

This project will be integrated and strengthened with the development of a national register, currently underway, on the model of the most relevant and consolidated CP registries in the world (the Australian and European CP Registries), through a network of researchers, clinicians and families, with the aim of identifying primary needs in this complex pathology.

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