National Surveillance of Cerebral Palsy in Portugal
Overview of the first 8 surveyed years (birth-cohorts 2001-2008)

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Background. Active epidemiological surveillance of cerebral palsy (CP) in childhood potentially provides evidence to evaluate trends of prevalence, severity and inclusion and to support adequate care. The surveillance of large populations and geographic areas provides hard data but presents problems of coverage, ascertainment and sustainability.

Aim. An updated overview of the first decade of the Portuguese National Surveillance of Cerebral Palsy among 5-years-old Children Program (PNSCP5YC) is presented.

Study Design, Methods, Study Participants & Setting. The PNSCP5YC is an ongoing population registry, based on birth-cohorts approached for analysis as multiple cross-sectional studies. The PNSCP5YC actively registers children with CP at the target age of 5, using multiple sources. It shares definitions, classifications and tools with SCPE. MRI is classified by its predominant pattern (Krägeloh-Mann et al.). Registry of confirmed cases of children deceased between the ages of 2 and 5 years is encouraged. Out of 1191 registered children with CP, 1105 survivors at 5 years of age (635 boys, 57.5%), born in 2001-2008 and living in Portugal in 2006-2013, were included for analysis.

Results. The birth-cohort prevalence of CP at 5 years of age peaked in 2006 (those born in 2001), leveled in 2007-2008 and dropped afterwards (Figure 1). Those born at term were 54.6% (41.0-59.1), 93.6% had been born in Portugal. A post-neonatal cause was identified in 8.1%. MRI was performed in 76.2% and was amenable to be classified in 46.5% (Figure 2). CP was spastic in 83.9% (79.4-87.7), bilateral in 66.4% (59.8-75.3) (Figure 3). GMFCS grades IV-V were reported in 41.9% (33.8-52.2) and BFMF grades IV-V in 39.5% (30.3-52.2 ) (Table).

Conclusions/Significance. Active epidemiological surveillance of CP is a powerful tool to describe this condition on a population with a geographic basis. Maintaining large scale surveillance requires a great effort to reach adequate coverage and representativeness. Multiple sources and recapture strategies have to be used to achieve an accurate description of this condition, particularly on a regional basis. Special care should be taken when data from periods with inadequate coverage are analyzed.