The SCPE Central Registry including the Central Database is being transferred to the European Commission’s Joint Research Centre (JRC) as part of the EU Platform on Rare Diseases Registration developed by JRC in collaboration with DG SANTE.

History

The Surveillance of Cerebral Palsy in Europe (SCPE) was established in 1998 as a collaboration of professionals and researchers working with CP registers, including epidemiologists, pediatric neurologists, orthopedic surgeons, physiotherapists, occupational therapists, speech and language therapists and nutritionists.

The aim was to develop a common database of children with CP in order to:
• Monitor trends in CP.
• Provide a framework for collaborative research.
• Provide information for service planning and raise standards of assessment and care for children with CP.

The original network consisted of 14 centres in eight European countries. At present, the SCPE comprises 24 active centres in 20 countries: Austria, Belgium, Croatia, Denmark, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Malta, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland, United Kingdom.

Each centre collects information about all children born with CP within a region, and sends a common data set to the SCPE Central Database. Data is then pooled and specific analyses, such as assessing the rate of CP in very low birth weight babies, are performed. The collaboration is examining variations in clinical practice across Europe, access to health care and further refinement of how children with cerebral palsy are described. As of 2016, the SCPE common database contains anonymized population data on 19000 children with CP.
What is cerebral palsy (CP)?

Cerebral palsy is the term for a range of movement difficulties which are caused when the parts of the brain which control such movements do not work properly. It is the most common cause of significant physical impairment in children. Because cerebral palsy is due to the brain being malformed or damaged, there are often associated difficulties of vision, hearing, intellect, communication and feeding. The condition may affect a child’s well-being and their ability to participate fully in life. Prevalence of CP is about two babies per 1,000 live births.

Reference and Training Manual (RTM) Tools

The SCPE have developed a range of tools to facilitate the identification and description of CP, and enable collaboration across Europe. These include:
1. Decision tree for cerebral palsy
2. CP subtypes according to neurological findings
3. Classification tree of CP subtypes
4. Neuroimaging and neonatal neuroimaging classification
5. Illustration of CP clinical cases by CP definition
6. Viking Speech Scale

Recent Publications


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