



Surveillance of Cerebral Palsy in Europe:
best practice in monitoring,
understanding inequality
and dissemination of knowledge
SCPE-NET



World CP Registers, Surveys and Networks Day

4th International Cerebral Palsy Conference

Pisa – October 11, 2012

The first World Cerebral Palsy Registers Day was organised in Sydney 2009 as part of the 3rd International Cerebral Palsy Conference http://www.cpresearch.org.au/pdfs/conference_proceedings.pdf. Following its success, it was proposed to hold the 2nd WCPRD during Pisa 2012 ICPC <http://www.cp2012.it/>.

The aim of this World Cerebral Palsy Registers Day (WCPRD) is **to share best practices with other CP registers, surveys and networks and to demonstrate the impact of CP registers in the care and management of children and adults with CP.**

This WCPRD will be organised as a day long series of four symposia, compatible with attendance of the plenary sessions within the general International CP Conference programme.

Preliminary programme of this WCPRD contains four symposia of 90 minutes each:

- Challenges in describing and classifying children with CP
- Challenges in estimating prevalence of CP and recent trends
- Harmonisation in neuro-imaging
- Quality of care, including transition to adulthood: how registers can help?

Challenges in describing and classifying children with CP

The aim of the session is to improve consistency around the world in the way children with CP are described. Professionals in charge of registration of children with CP face similar challenges, and harmonisation of collected data can be very helpful in the interpretation of research results.

This symposium will discuss i) how conditions often associated with CP such as birth defects, and conditions excluded from the CP field such as progressive disorders are managed across the world and ii) methodological issues regarding data quality and reliability when including or classifying children with CP.

Challenges in estimating CP prevalence and recent trends

The aim of the session is i) to provide a forum to discuss the current challenges associated with measuring and interpreting estimates of prevalence and trends of CP, and ii) to summarise data on estimates of prevalence and trends around the world.

Some examples of challenges include: “in” and “out” migration from the geographical area under study, neonatal survival and/or death of young children with signs of CP who die before age at registration, changes in environmental/social systems and health care on the likelihood of case ascertainment, impact of requiring consent for registration.

Harmonisation in neuro-imaging

The aim of the session is to provide a forum for exchange of ideas on how to deal with imaging finding in CP registers, and to discuss suggestions for classification of neuro-imaging results by CP registers.

Neuro-imaging, neonatal and post-neonatal, is often abnormal in children with CP and helps to understand aetiology or at least pathogenesis of the underlying brain disorder. MRI has become an important diagnostic step after history taking, classifying CP subtype and the additional conditions.

In preparation for this symposium, a survey on neuro-imaging practice and findings will be performed with CP registers around the world; results of this survey will be presented during this session.

Quality of care, including transition to adulthood: how can registers help?

The aim of this session is to understand better how registers can be used to monitor and to improve quality of care for children and young people and their families.

Using registers to improve quality of care has three important benefits: care is improved, data quality on the register is improved through regular two-way exchange of data between register and clinical teams, and care is monitored and improved for all children in a geographical area, not just those attending a particular service or hospital.

WCPRD Pre-Programme: list of speakers, as of June 5, 2012	
Thursday 11 October 2012	
10.45 World CP Registers, Surveys and Networks Day at Pisa 2012 ICPC	
10.50 – 12.20: Challenges in describing and classifying children with CP	
Christine Cans, FR-SCPE	Moderator
Nadia Badawi, AU	Challenges in cerebral palsy surveillance: seeking harmony in inclusion and exclusion criteria.
Marshalyn Yeargin-Allsopp, US	Exclusion of progressive brain disorders of childhood for a cerebral palsy monitoring system
Sarah Love, AU	Reliable description of motor impairments in children with CP
Oral communications:	
Elodie Sellier, FR-SCPE	Reproducibility studies of the SCPE inclusion/classification system for cerebral palsy
Elegast Monbaliu, BE	The Use of the Dyskinesia Impairment Scale by less experienced raters: a reliability study
Rebecca Yin Foo, AU	Systematic review of intelligence assessments for children with cerebral palsy
12.20 – 13.50: Challenges in estimating CP prevalence and recent trends	
Mary Jane Platt, UK-SCPE	Moderator
Eve Blair, AU	Issues in estimating prevalence and trends in cerebral palsy
Kim van Naarden Braun, US	Role of migration and choice of denominator on the prevalence of cerebral palsy
Oral communications:	
Linda Watson, AU	Achieving mandatory notification of cerebral palsy in Western Australia - a success story
Susan Reid, AU	Rates of cerebral palsy in Victoria, Australia, 1970–2004: has there been a change?
Antoni Monserrat (tbc), EU	Guest speaker, EU Policy on Neurodevelopmental and Rare diseases
16. 40 – 18.10: Harmonisation in neuro-imaging	
Ingeborg Krägeloh-M, DE-SCPE	Moderator
Veronka Horber, DE-SCPE	How to register neuroimaging findings in children with CP – a classification suggested by the SCPE
Sue Reid, AU	Classification of MRI in cerebral palsy: findings from an Australian study and review
Javier de la Cruz, ES-SCPE	How do CP registers record neonatal neuroimaging information: a survey
Oral communications:	
Eulalia Calado, PT	The diagnosis of cerebral palsy with a normal brain MRI. How far do we feel confident?
María López-M, ES	Severe intraventricular haemorrhage and parenchymal lesions in VLBW neonates: trends over 20 years
18.10 – 19.40: Quality of care, including transition to adulthood: how can registers help?	
Allan Colver, UK-SCPE	Moderator
Jane Hutton, UK	Life-expectancy in cerebral palsy
Kate Himmelmann, SE	Development of a clinical research programme around a CP register – improving quality of care
Karen Horridge, UK	Using a register to audit quality of care
Oral communications:	
Sandra Hollung-J, NO-SCPE	How is growth and nutrition assessed in European children with cerebral palsy?
Magnus O Dalhseng, NO-SCPE	Gastrostomy tube feeding of children with cerebral palsy: variation across 6 European countries
Rachel Jordan, AU	Cost of medical & allied health resource use in preschool age children with cerebral palsy
19.45 Reception for all participants to the 2012 WCPRD	
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