**Session Programme**

2. A comparison of European and Australian networks of CP registers: Methods (*Dr E Sellier & S McIntyre*)
3. Surveillance of Cerebral Palsy in Europe and Australian Cerebral Palsy Register: prevalence, severity and associated impairments, CP and preterm births (*Dr C Arnaud & S McIntyre*)
4. Discussion: *Dr G L Andersen, Dr C Arnaud, S McIntyre, Pr MJ Platt, & Dr E Sellier*

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**An overview of the epidemiology of CP in Europe**

*Professor Mary Jane Platt*
Norwich Medical School

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**In the beginning...**

- Genesis 1
  - “God saw all that he had made, and it was very good”
- Several Millenia later...
  - Christine Cans had another good idea...
Cerebral Palsy is a group of permanent, but not unchanging disorders of movement and/or posture and of motor function. Which are due to a non-progressive interference, lesion, or abnormality of the developing/immature brain.

Birth prevalence:

- the number of babies born to mothers residing in a specific geographically defined area/region in the specified year, who are diagnosed with CP by the age of 5 years, compared to the total number of live births to mothers resident in the same area during the same birth year.

Birth Prevalence

Overall Prevalence of CP

- 5 working groups & many hours of discussion later lead to DATA HARMONISATION
- Data on 3689 resident cases from 3.3 million live births from 1980-90
- Mean prevalence rate of 2.08 per 1000 (2.02-2.14) Individual centres ranging 1.49-2.63
‘Severe’ CP: Birthweight-specific prevalence

(DMCN 2002; 44:633-640)

- Birthweight-specific prevalence (1980-1990)
  - <1500g: 72.6
  - 1500-2500g: 11.1
  - >2500g: 1.2
- Prevalence of ‘Severe’ CP
  - 0.43 (0.4-0.46)
- Data on profile of those with CP
  - Subtype (85.7% spastic)
  - Level of impairment
    - (severe cognitive impairment and unable to walk) 20%

VLBW-Specific Prevalence of CP 1980-1996

(Lancet 2007;369:43-50)

- 1980’s saw improved survival of VLBW infants
- But how did this impact on CP prevalence among VLBW infants?
- Prevalence of CP among VLBW infants
  - 1980-1996
    - <1000g: 40.0 (n=353)
    - 1000-1499g: 56.1 (n=961)

VLBW-Specific Prevalence of CP 1980-1996

- Moderately preterm (GA 32-36 week, n=1664)
- Year-on-year decline of 3%
- Similar pattern in MLBW-Specific Prevalence of CP (BW 1500g-2499g, n=2159)
  - From peak of 11.3 (1987) to low of 6.5 in 1996

VLBW-Specific Prevalence of CP 1980-1996

- From 60.6 (37.8-91.4) to 39.5 (28.6-53.0)
- Most notably in those 1000-1499g infants with bilateral spastic CP (n=717)
- <1000g
  - Unstable, but overall fall from 64.2 to 29.4

Analysis by GA (<28 week, 28-31, n=528) smaller numbers, but similar pattern
(Blank 2011;53:913-919)

As with VLBW infants, decline seen principally among those with bilateral spastic CP

Prevalence of CP in infants of ≥ 2500g 1980-1998
(Eur J Epidemiol 2010;25: 635-642)

Among children of BW ≥ 2500g, (n=4002)
Overall prevalence of 1.14
Non significant decline over time from 1.16 (1980) to 0.99 (1998)
Significant decline in prevalence of bilateral CP
From 0.58 (1980) to 0.33 (1998)
Some increase seen in Unilateral spastic CP (0.37 to 0.46)

Further progress

• By 2003: SCPE held data on over 10,000 children with CP from 20 centres covering population of 5.3x10^6 LB

• Definition of Moderate-Severe CP:
  • IQ <50 or GMFCS 3 or higher/unable to walk without assistive devices

0.7% per annum Prevalence decline 1980-2005
(DMCN 2015;58:85-92)

Decline of 3.4% per annum
Stable rates among ELBW

Non linear decline
Summary

- Significant reduction in prevalence of all CP, and moderate/Severe CP in VLBW and MLWB infants
- Non significant decline in prevalence of CP in NBW, with stable CP rate in ELBW infants
- Significant reduction in birth prevalence of Bilateral spastic CP seen in all BW groups except ELBW
- Significant increase in Unilateral spastic CP among NBW, otherwise stable rates

Dyskinetic CP

(Research in Developmental Disabilities 2013;34:1669-77; Perinatal and Paediatric Epidemiology 2004;18:214-220)

Post Neonatal CP

CP in Multiple births

(Arch Dis Child 2009;94:921-926)

(Acta Obstet Gynecol Scand 2004;83:548-553)
Spectrum

1995

prevalence

of

those

among

Children

with

more

than

those

with

CP

without

ASD

to

be

Male,

independent

walkers,

and

have
current

epilepsy

Wide

centre

limits

Impairments

Congenital

malformations:

1976

1996, 11.9%

Those

with

have

CM.

Although

CM

common

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CP

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Child

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1976

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79

Neurol2012;16:48

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55

742)

perinatal

stress

Jarvis, S., Glinianaia, S.V., Torrioli, M.-G., Platt, M.-J., Miceli, M., Jouk, P.-S., Johnson, A.,
Hutton, J., Hemming, K., Hagberg, G., Dick, H., Dickson, J., and Surveillance of Cerebral Palsy in
Europe (SCPE) collaboration of European Cerebral Palsy Registers (2003). Cerebral palsy and
intrauterine growth in single births: European collaborative study. The Lancet, 362(9390), pp.1106–
1109.

and environmental factors in the pathogenesis of cerebral palsy. Developmental Medicine &


Our findings indicate that CP is an outcome indicator for obstetric and neonatal care. Our work has demonstrated the long term impact of improvements in obstetric, neonatal and paediatric care in terms of a reduction in prevalence of CP across Europe.

Key findings include:
- significant decline in birth prevalence of bilateral Spastic CP in all groups other then ELBW
- reduction in total prevalence in MLBW and VLBW infants
- reduction in prevalence of Post Neonatal CP associated with infection

Conclusion