



The Victorian Cerebral Palsy Register: learning more about cerebral palsy

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Cerebral palsy

- Cerebral palsy is a disorder of movement and posture due to a defect or lesion of the developing brain
- Most common cause of physical disability in childhood



Major gaps in knowledge

- In many cases the risk factors and cause or causes remain largely unknown
- The outcomes of treatment remain uncertain





Purposes of Registers

- To study trends in rates of cerebral palsy – are the numbers increasing, decreasing or staying the same?
- To gather cohorts for aetiology and outcome studies
- To generate data for medical, disability and education providers for planning and to contribute to national dataset

The Victorian Cerebral Palsy Register

- Young people born in Victorian since 1970, others also recorded
- Definite diagnosis of cerebral palsy
- Includes acquired cerebral insults up to the age of six years



How is information collected?

- Outpatient clinics and inpatient admissions:
Royal Children's Hospital, Monash Medical Centre
- Scope
- Paediatricians
- Family self report
- Linked to Perinatal Data Collection Unit

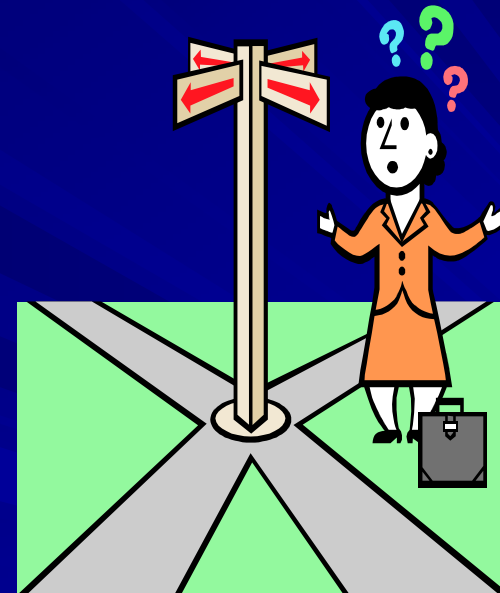
What information is gathered?

- Birth details
- Cause or causes where known
- Motor type, distribution and severity of the motor problem (GMFCS & MACS)



What information is gathered?

- Associated problems, eg, presence of epilepsy, visual impairment
- Interventions, eg, botulinum toxin therapy, intrathecal baclofen and saliva control surgery

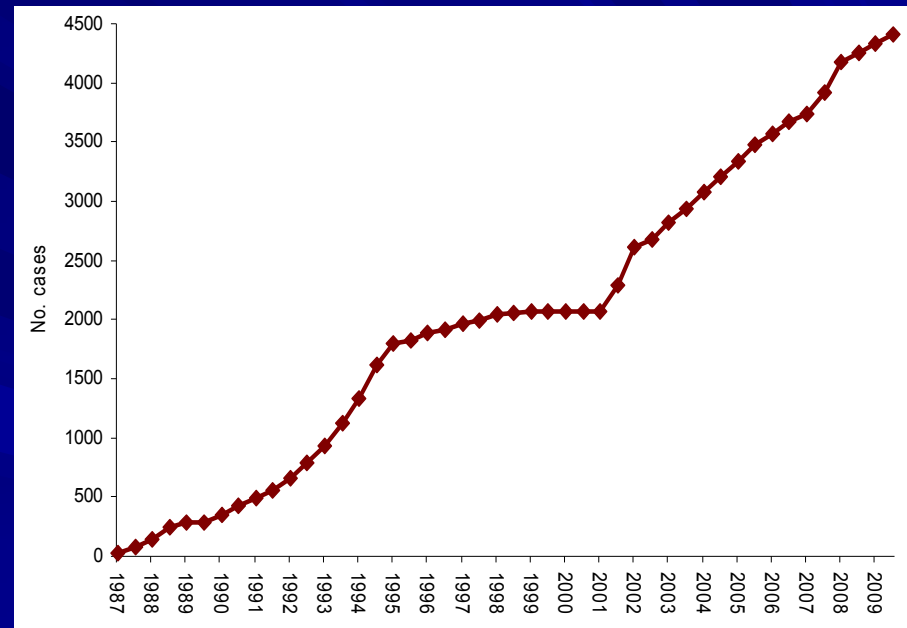


Ethics approval

- The Royal Children's Hospital Human Research Ethics Committee
- Southern Health Human Research Ethics Committee
- Scope Victoria

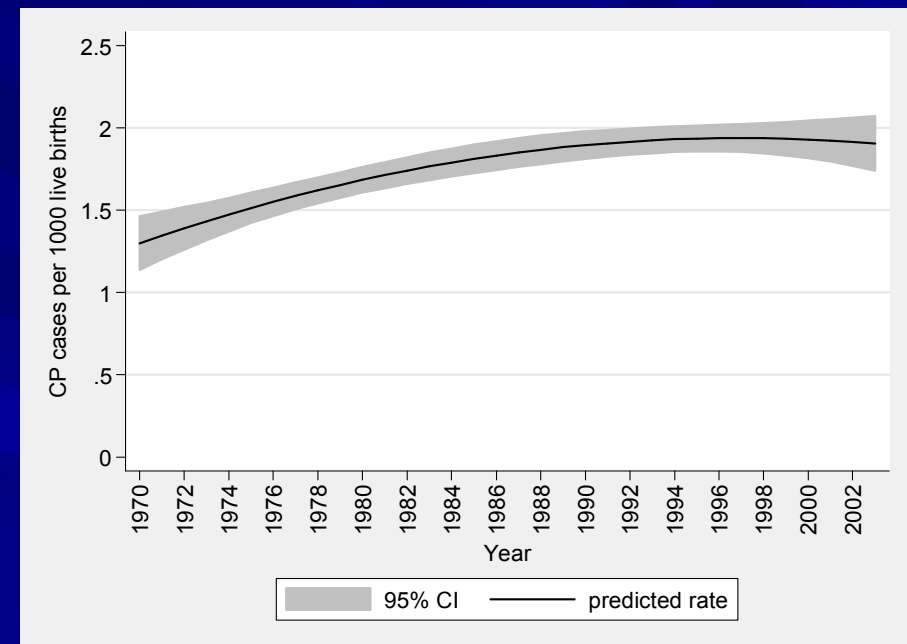
Children with cerebral palsy in Victoria

- 4,405 young people on the Register born since 1970
- 59% male
- 1.3% indigenous



Birth prevalence of cerebral palsy

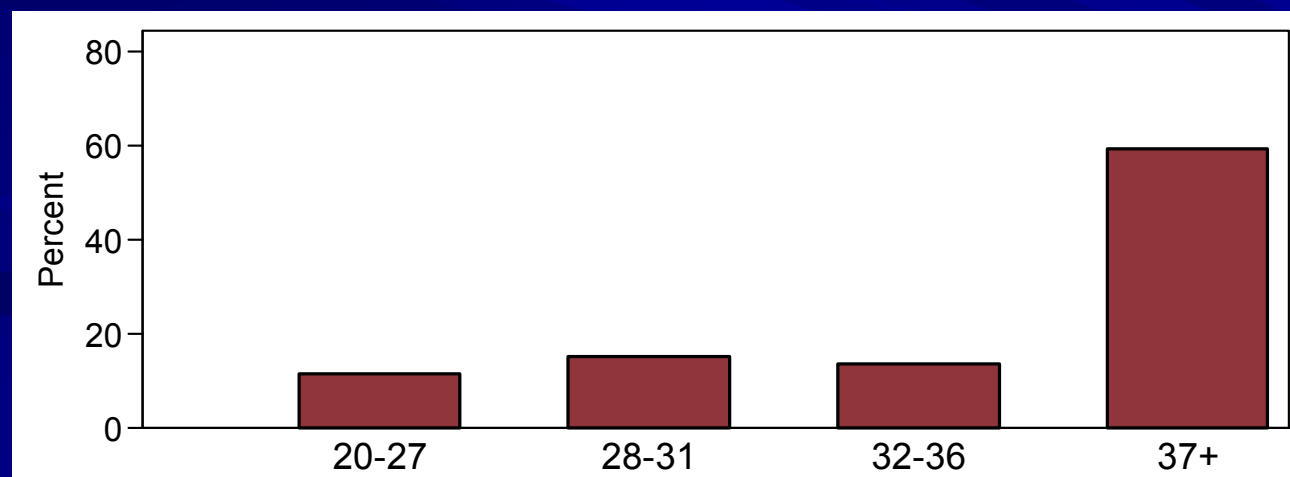
- Over the period 1970 – 2003, birth prevalence was 1.8 cases /1000 live births
- 11% of individuals had died



Gestational age at delivery

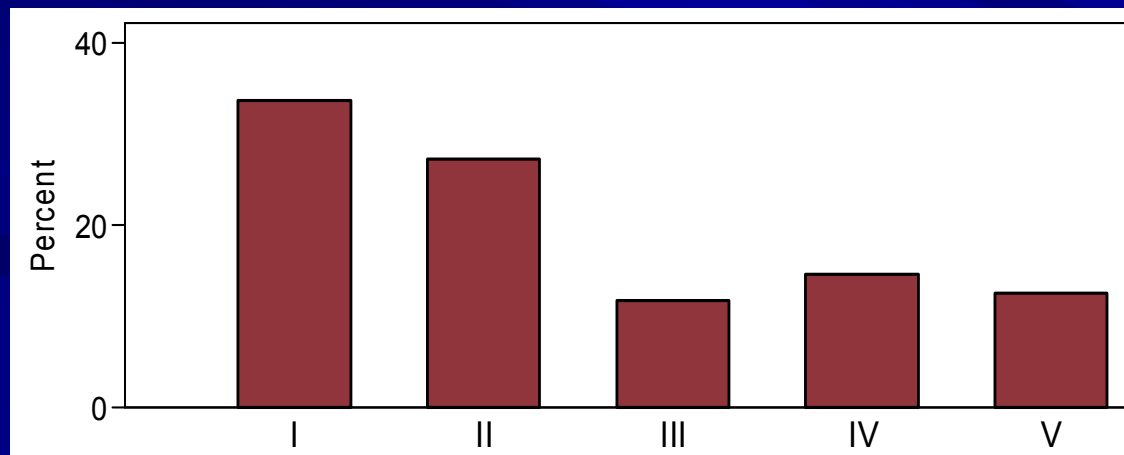
Children born 1990 – 2005 (n=1,630)

- Nearly 60% were born at term (59.4%)
- Only 12% were born in the high risk extremely premature group



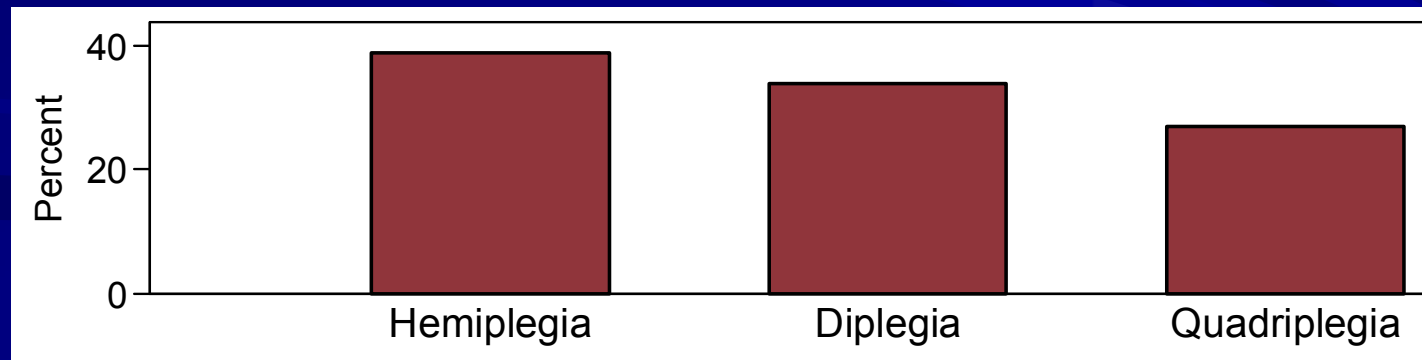
Severity of the motor disorder

GMFCS	n	(%)
Level 1	524	(33.7)
Level 2	425	(27.3)
Level 3	183	(11.8)
Level 4	228	(14.7)
Level 5	195	(12.5)
Total	1,555	(100.0)



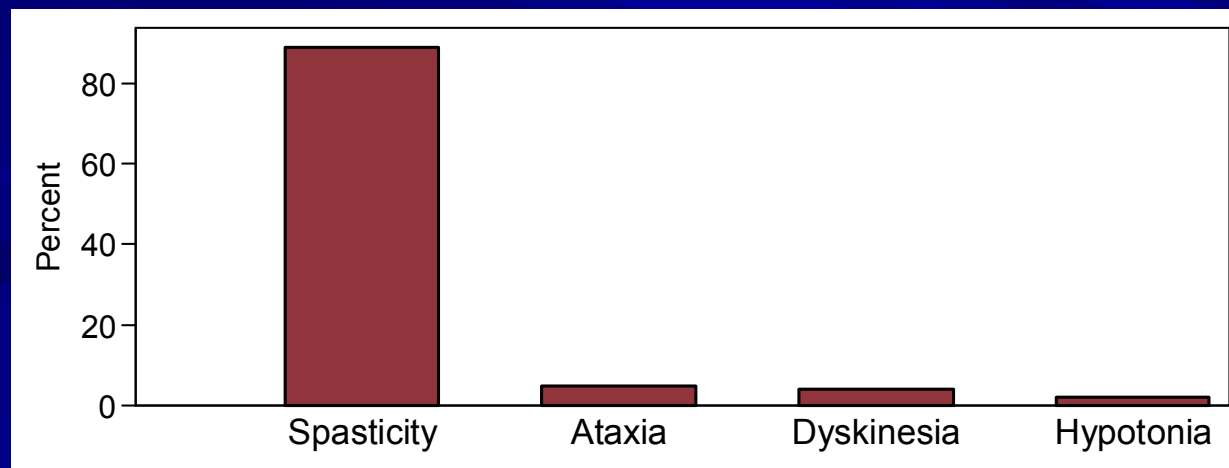
Topographical pattern of motor disorder

Topography	n	(%)
Hemiplegia	571	(39.0)
Diplegia	498	(34.0)
Quadriplegia	397	(27.0)
Total	1,466	(100.0)



Type of motor disorder

Predominant motor type	n	(%)
Spasticity	1,466	(88.7)
Ataxia	81	(4.9)
Dyskinesia	71	(4.3)
Hypotonia	35	(2.1)
Total	1,653	(100.0)



Care needs – children born since 1990

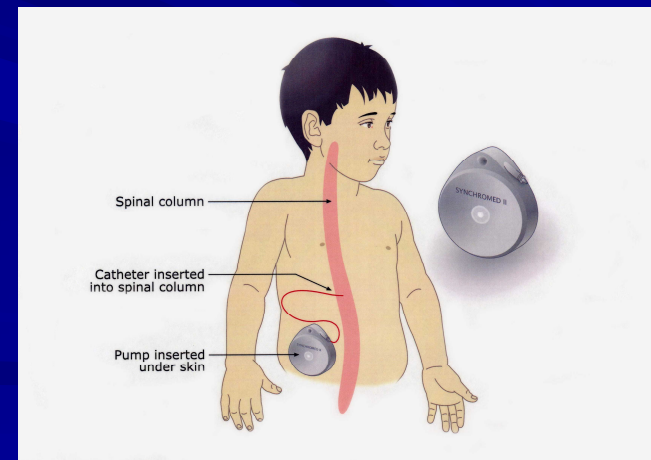
Associated problems

- 30% epilepsy
- 49.5% visual problems
- 13% hearing problems
- 49.5% intellectual impairment

Care needs

Medical interventions

- 54.5% botulinum toxin
- 8% gastrostomy feeds
- 0.7% intrathecal baclofen therapy



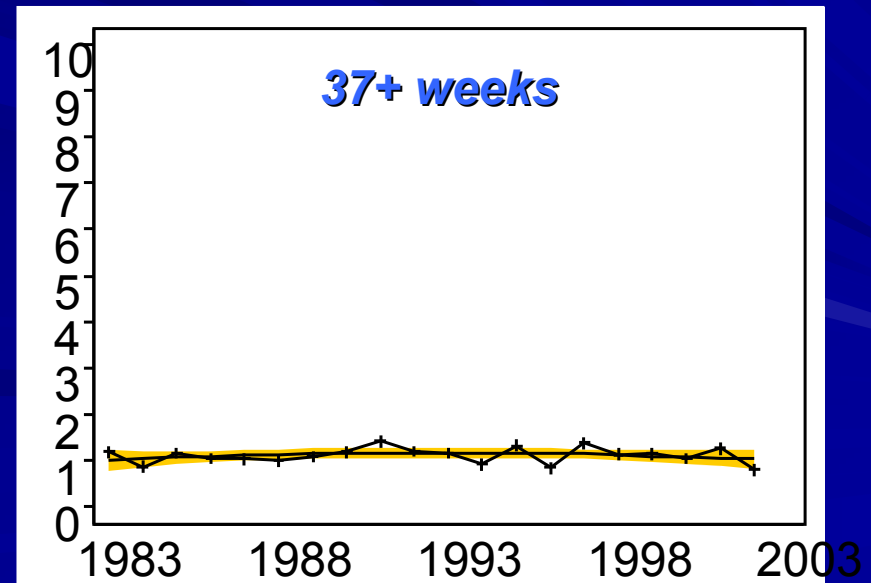
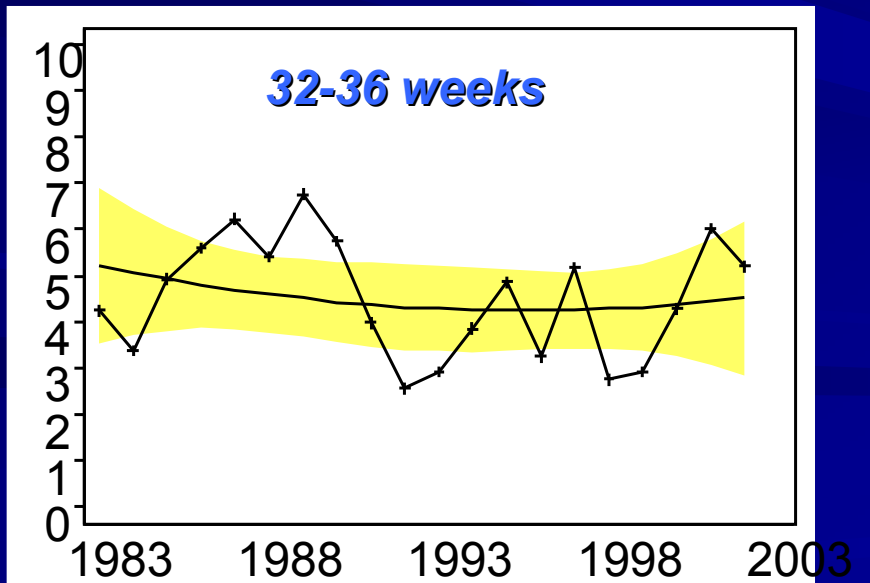
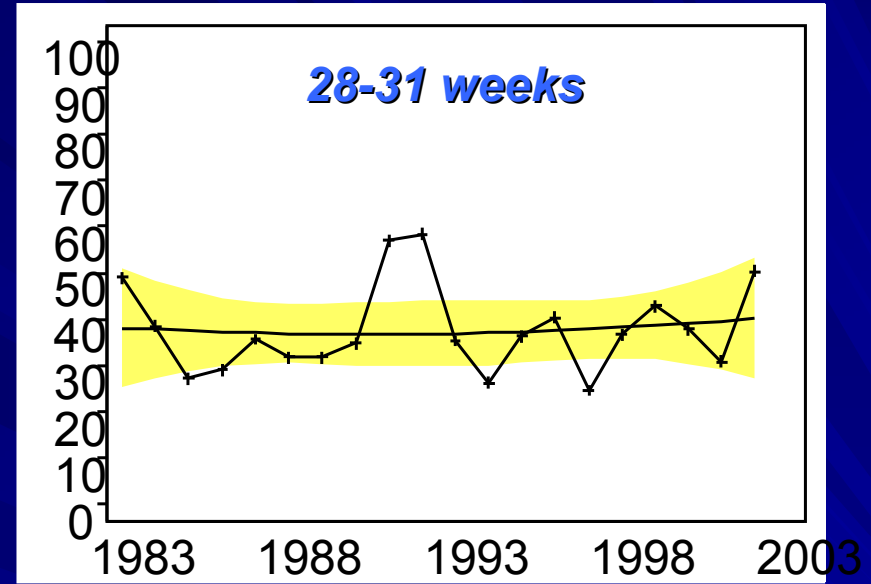
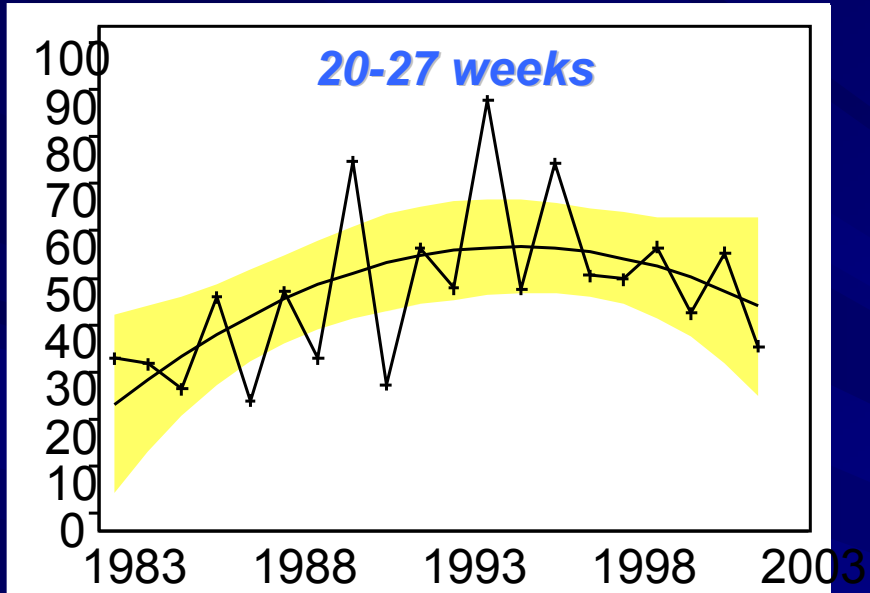
How does this help?

Many research projects helping us to understand more about:

- Epidemiology (12 studies)
- Causes and risk factors (10 studies)
- Outcomes (24 studies)

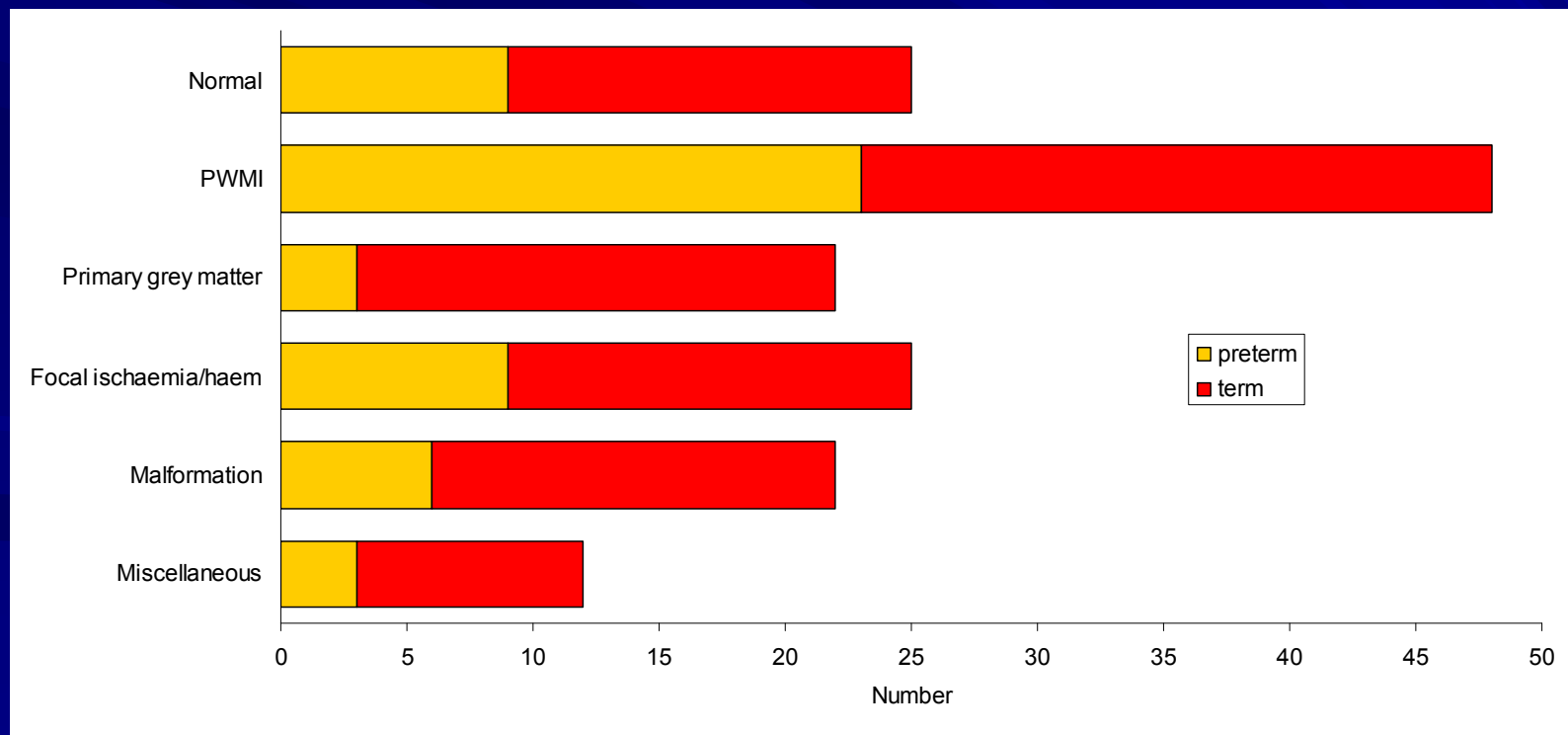


How does this help – epidemiology



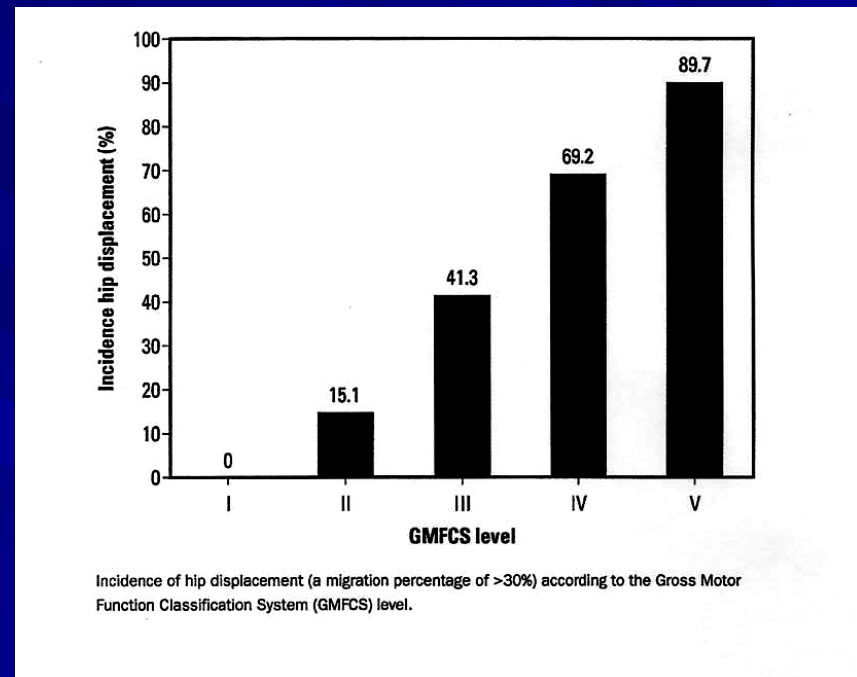
How does this help – risk factors and causes

- Population based study of all children with CP born in Victoria in years 2000 – 01
- 154 children had MRI's undertaken (70% of cohort)

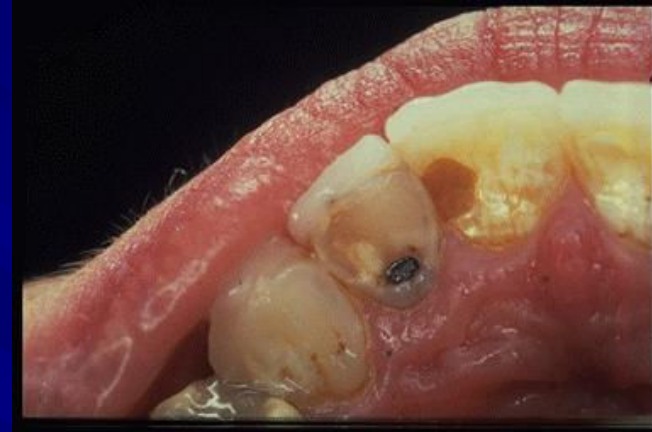


How does this help – outcomes

- Children with CP more likely to dislocate hips
- Data set of 323 (86%) of 374 children in the Register for years 1990 – 1992.
- The incidence of hip displacement linear with 0% for children with GMFCS level I and 90% for those with GMFCS level V.



How does this help – outcomes



- 19 children with cerebral palsy following surgery
- 75 other children with cerebral palsy
- Surgical group had significantly more caries than the comparison group ($P < 0.0001$)

How does this help - outcomes?

Development of measurement tools such as:

- The Melbourne Assessment of Upper Limb Function
- A Quality of Life Measure for Children with Cerebral Palsy (Cerebral Palsy Quality of Life Questionnaire for Children)





Thank you to our funding sources

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