

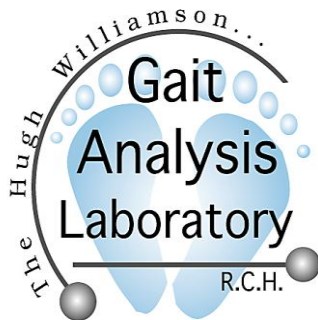
# Cerebral Palsy: Clinical and Epidemiological Aspects.

The Herman Robbins Lecture in Orthopaedics 2013.

Study Day Sponsored by The Ministry of Health and the Sackler Faculty of Medicine:

**”On the Quality of Life of People With Cerebral Palsy Across the Lifespan”**

H. Kerr Graham, Hugh Williamson Gait Laboratory  
Royal Children’s Hospital, Melbourne, Australia.  
King James IV Professor of Orthopaedic Surgery,  
Royal College of Surgeons, Edinburgh, 2012/13



# Herman Robbins MD

---

- **October 16<sup>th</sup> 1913 to June 15<sup>th</sup> 2008, NYC.**
- **Anderson Medical College, University of Glasgow.**
- **Graduated from University of Lausanne, 1941.**
- **WWII Captain and Battalion Surgeon, Europe.**
- **Awarded Purple Heart and Bronze Star, for heroism.**
- **Entered Paris with liberation troops.**
- **Orthopaedic Surgeon, Chairman of The NYU Hospital for Joint Diseases, 1972-1981 and a graduate, in 1955 of it's residency program.**

# Herman Robbins MD

---

- **Editor of The Bulletin of the Hospital for Joint Diseases 1979 to 1991.**
- **Taught LFA by Sir John Charnley in 1969.**
- **Pioneer in Paediatric Orthopaedics.**
- **Passionate about his family, his patients and Resident education.**
- **A 65 year career of service, education and leadership.**
- **This named lecture is dedicated to his memory.**

# Disclosures

---

- **Allergan: Research Support, Consultancy**
- **Botox Patent signed to Allergan for Gait Lab**
- **Merz (Xeomin) Consultant**
- **National Health & Medical Research Council of Australia, Clinical Centre of Research Excellence in Gait Rehab: NHMRC-CCRE**
- **Informed consent to show photos & videos**
- **Compliance with institutional requirements**

# Cerebral Palsy: Current Definition

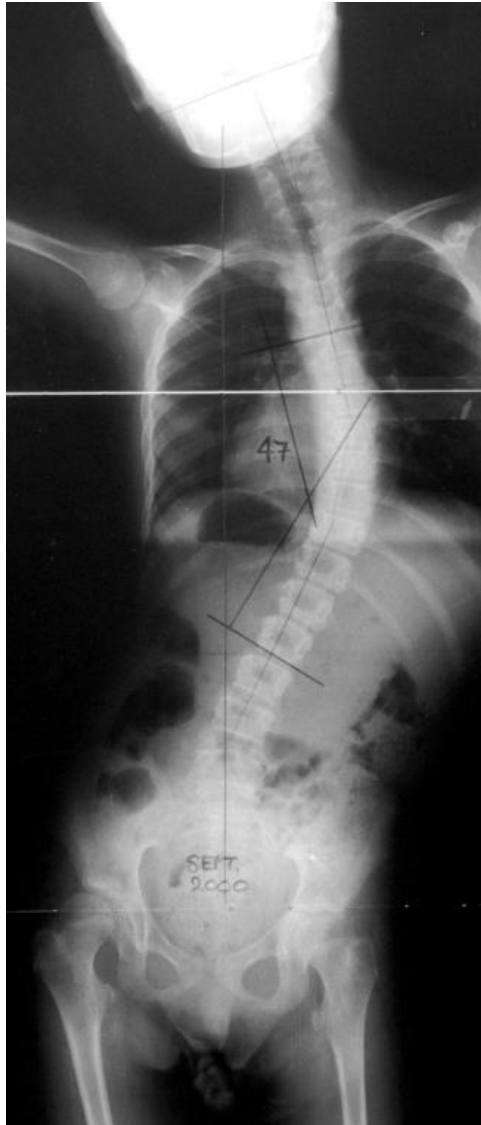
---

**A group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.**

**The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.**

**Definition & Classification of Cerebral Palsy: Rosenbaum et al**

**“Out of the crooked timber of humanity,  
no straight thing was ever made.”**



# Cerebral Palsy: Neuromusculoskeletal

---

- **The most complex neurological disorder,**
- **Compatible with medium/long term survival.**
- **The most common physical disorder, affecting children in developed countries.**
- **The most costly disorder to manage, across the lifespan.**

# Cerebral Palsy: Neuromusculoskeletal

---

- The most **complex** neurological disorder,
- Compatible with medium/long term survival.
- The most **common** physical disorder, affecting children in developed countries.
- The most **costly** disorder to manage, across the lifespan.



# Cerebral Palsy: Across The Lifespan.

---

- 1. Epidemiological Aspects**
- 2. Clinical Aspects.**
  - Population Based Research.**

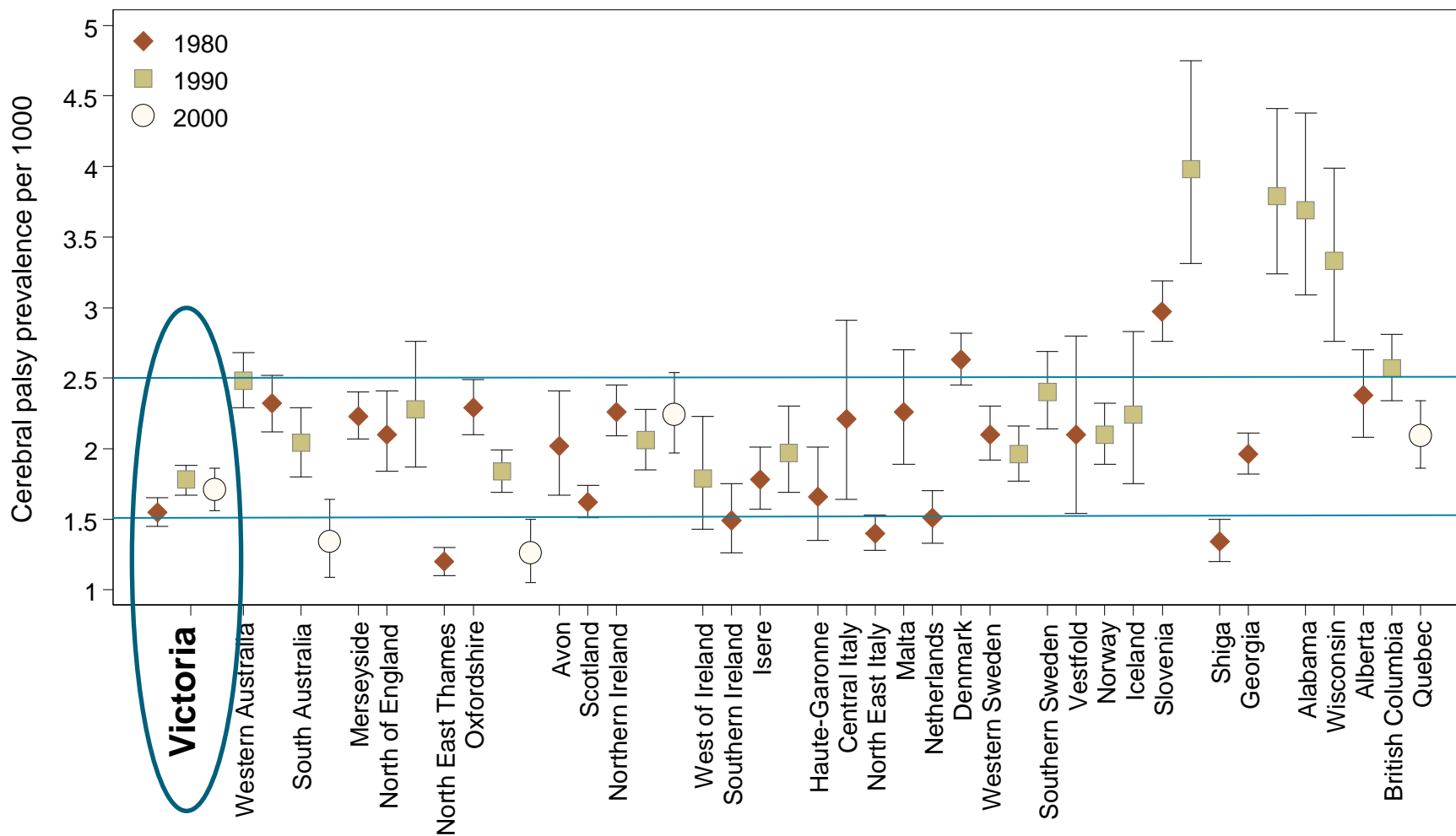
# Population Based Research: Cerebral Palsy Register: VCPR.



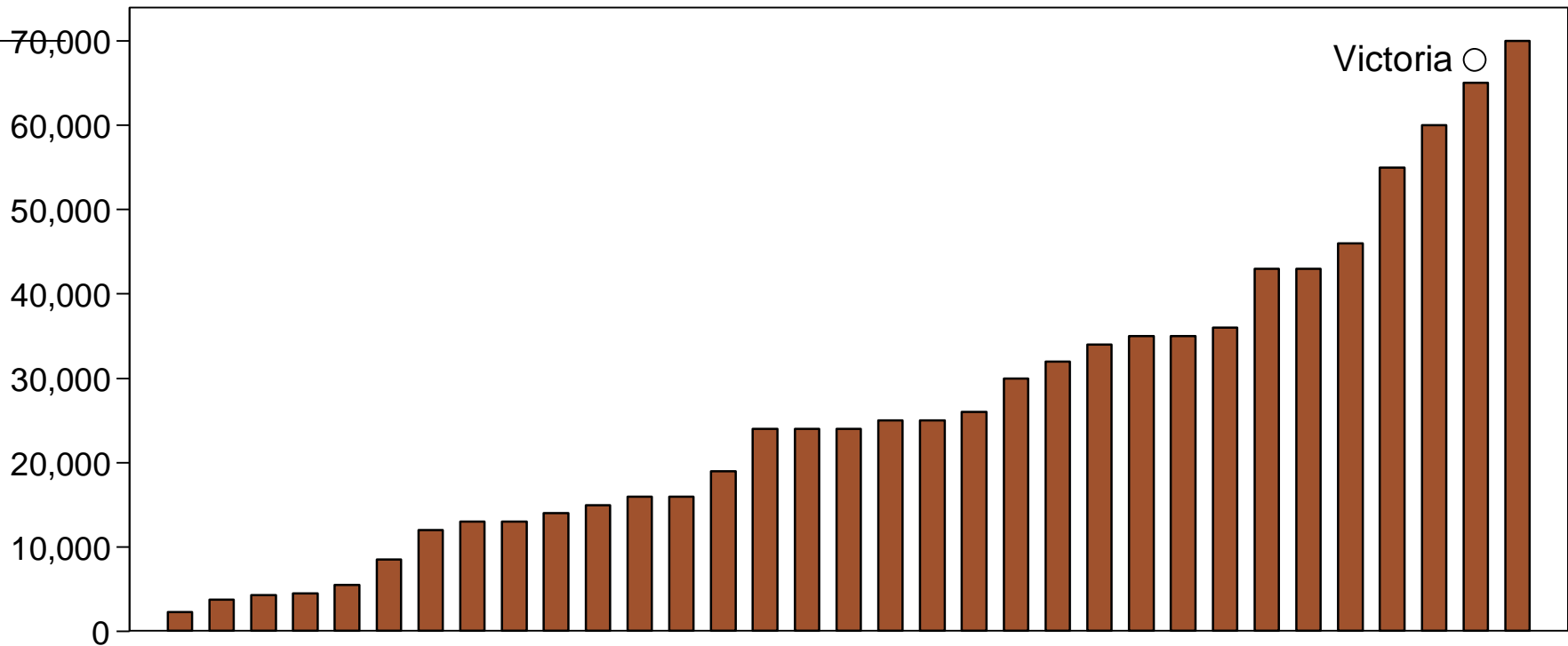
- Information about individuals with cerebral palsy born in Victoria since 1970.
- Linked to national register.
- Registration is by any MD and does not require consent.



# Prevalence of CP: 32 Registries

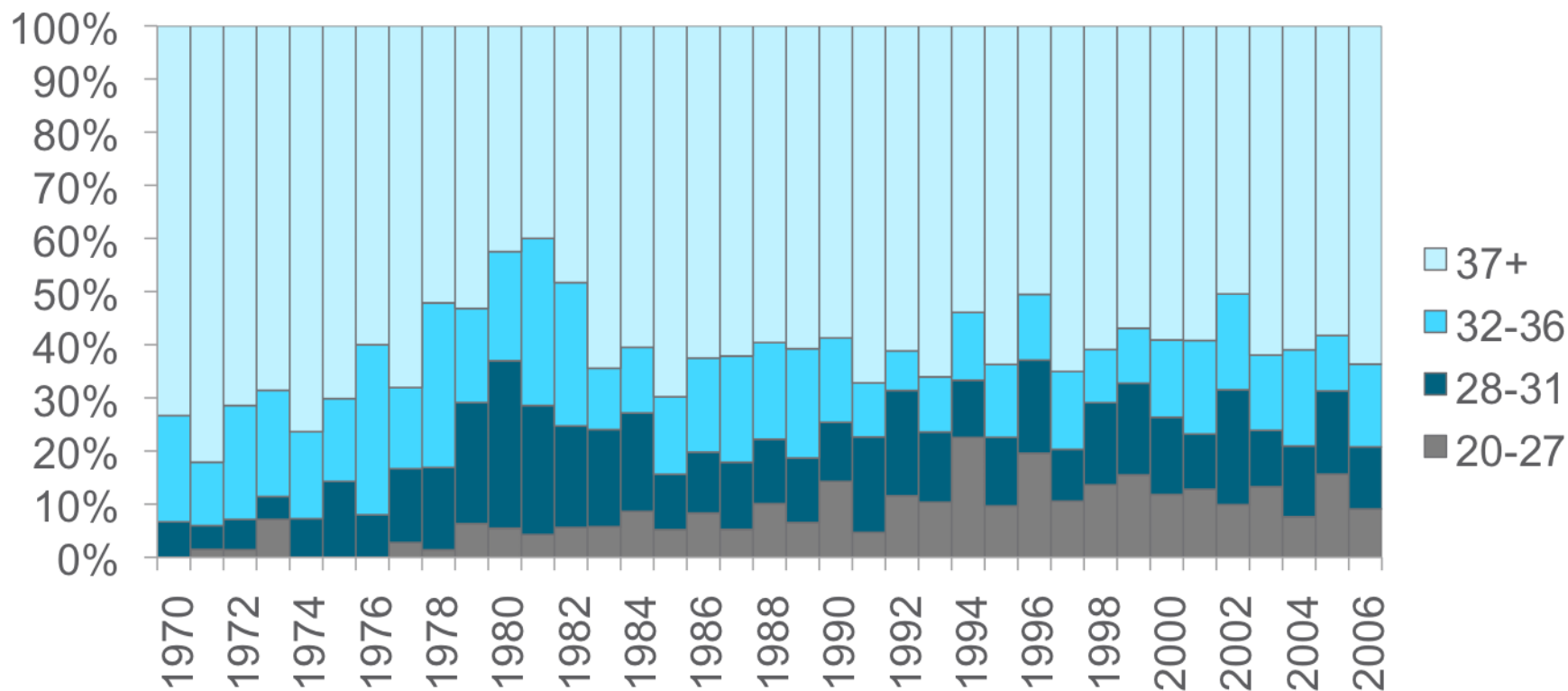


# Size of Denominator Population: 2<sup>nd</sup> largest CP register.



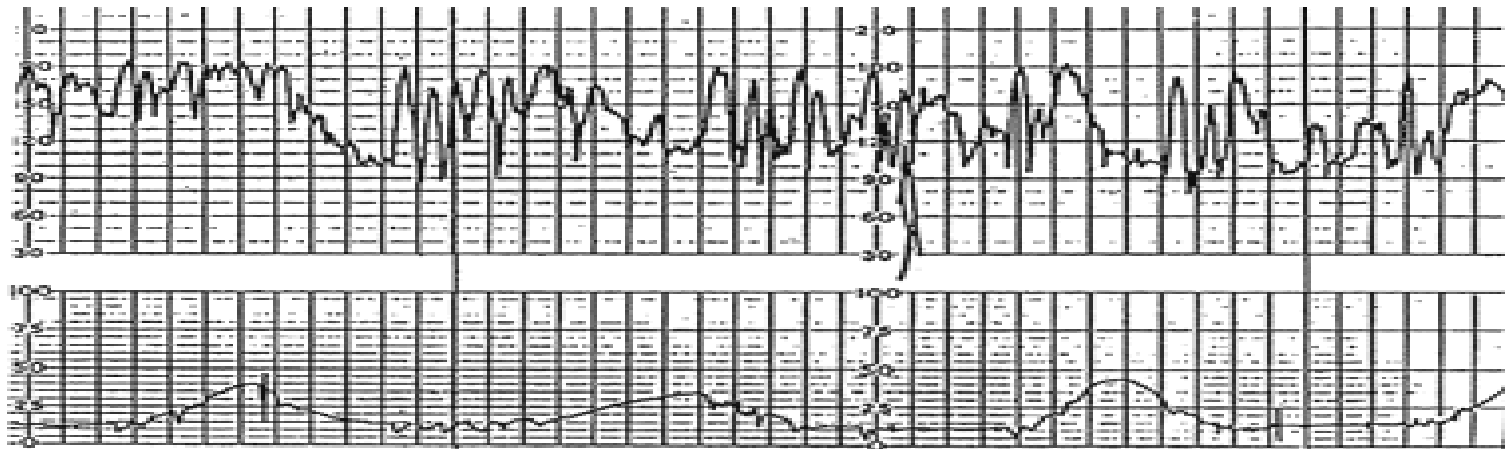
# Gestational Ages, 1970 - 2006

1. Premature birth is the major CP risk factor
2. Most children with CP, were term births.

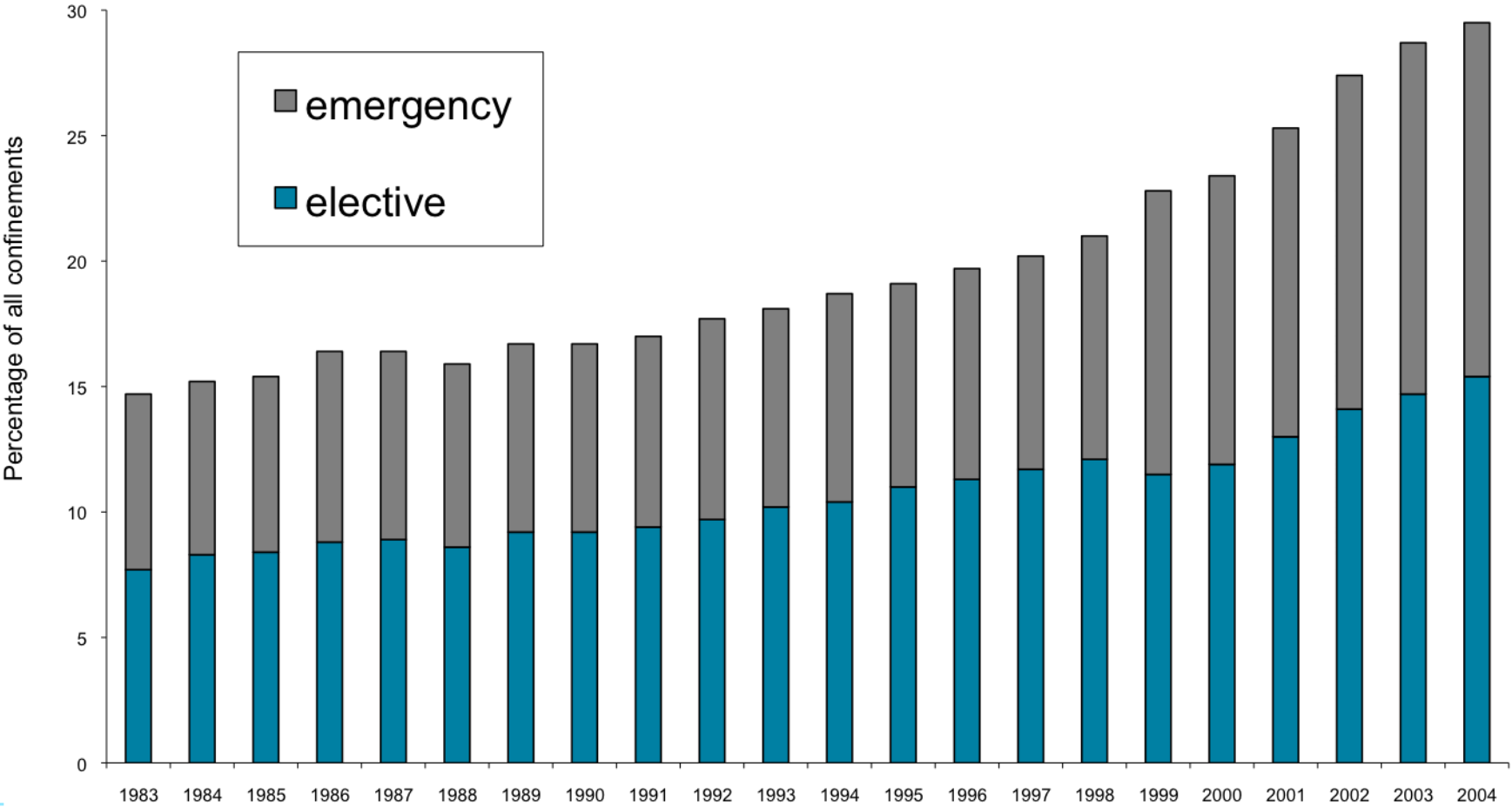


# CP: Not Caused by Poor Obstetrics.

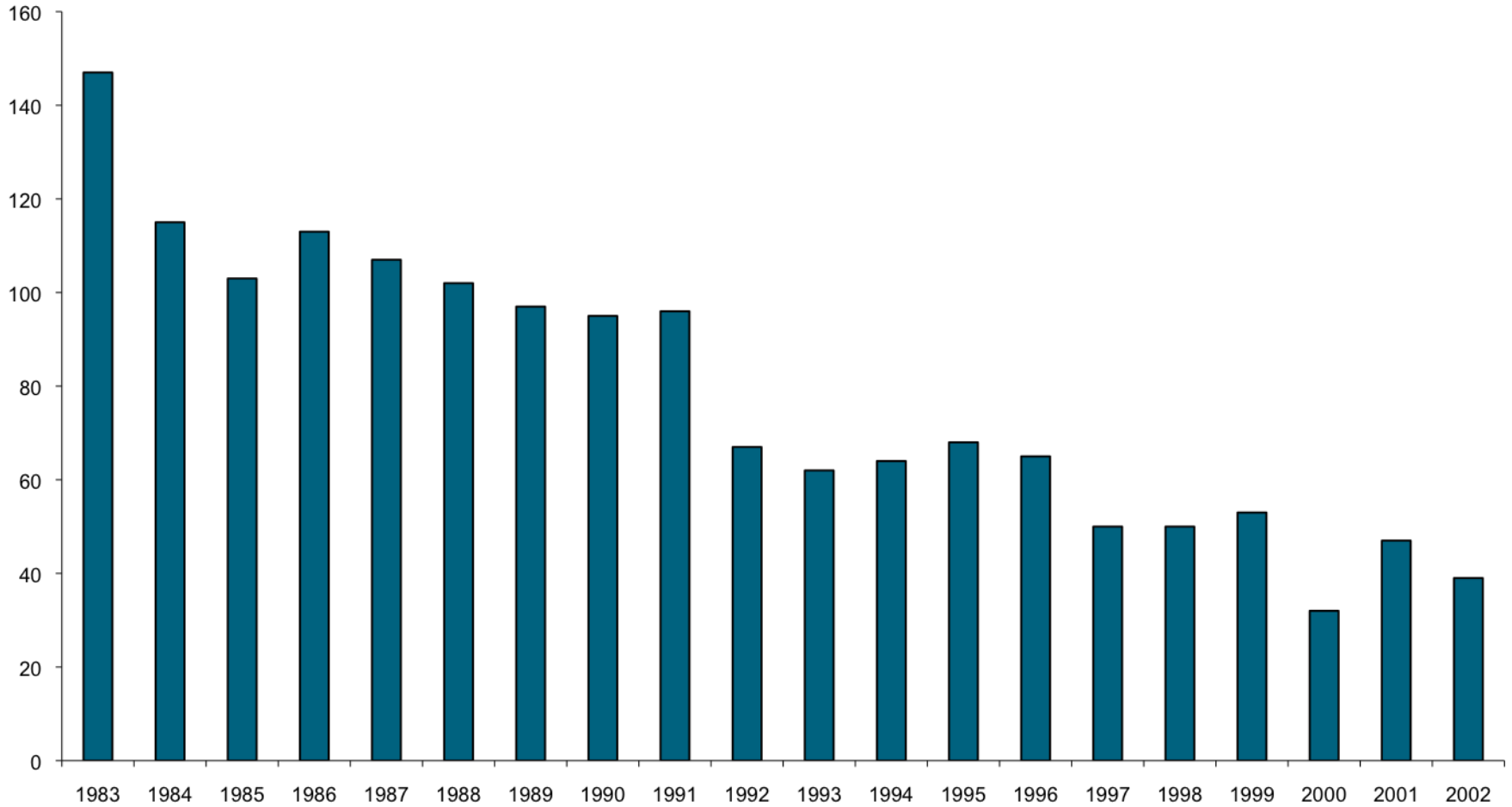
1. CP was thought to be largely due to intrapartum hypoxia and obstetric difficulties.
2. Hopes of reducing CP through fetal heart monitoring / caesarean section.



# C Section Rates: Soared 1983-2004

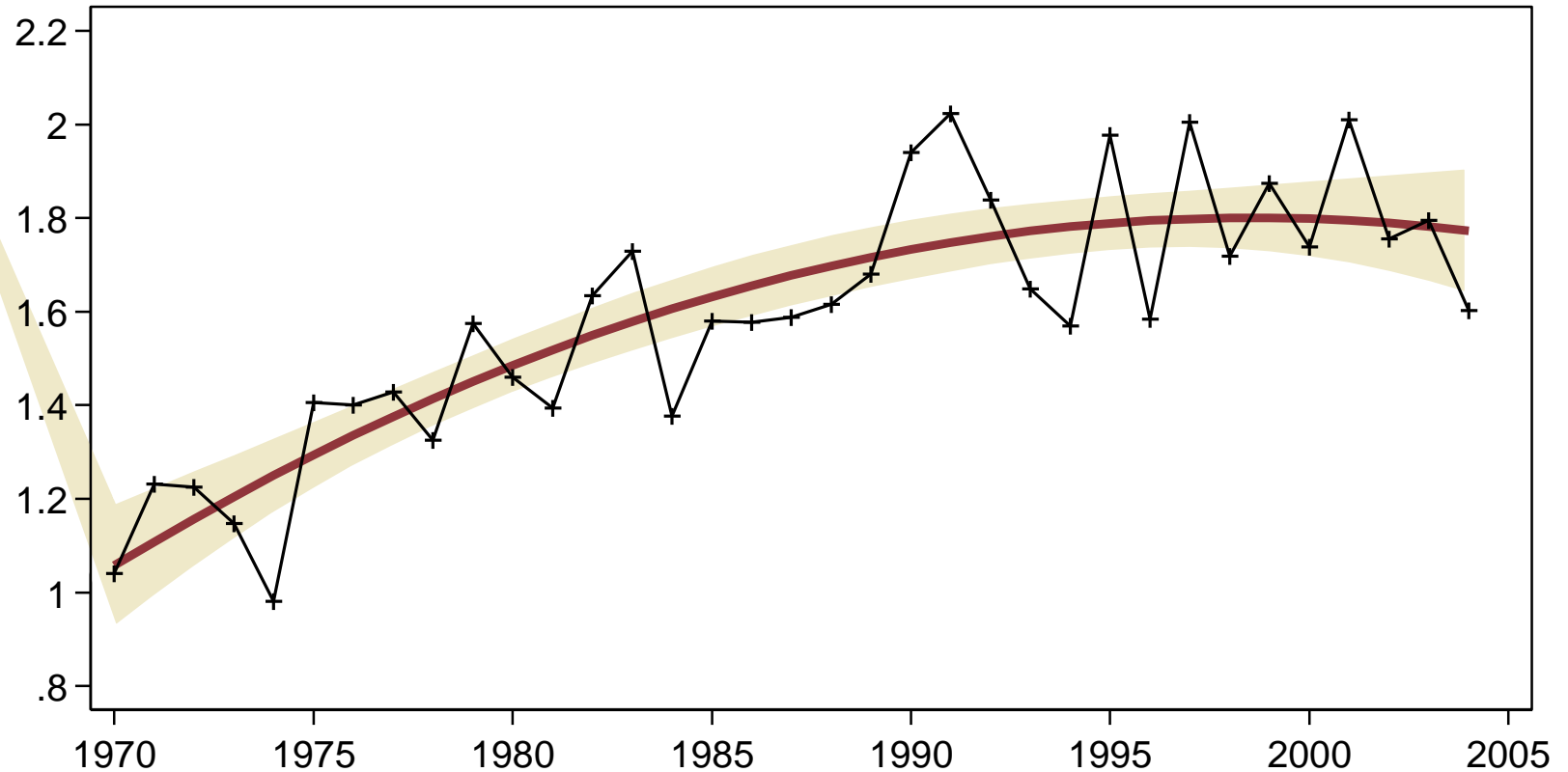


# Maternal Deaths: Fallen Sharply, 1983-2002

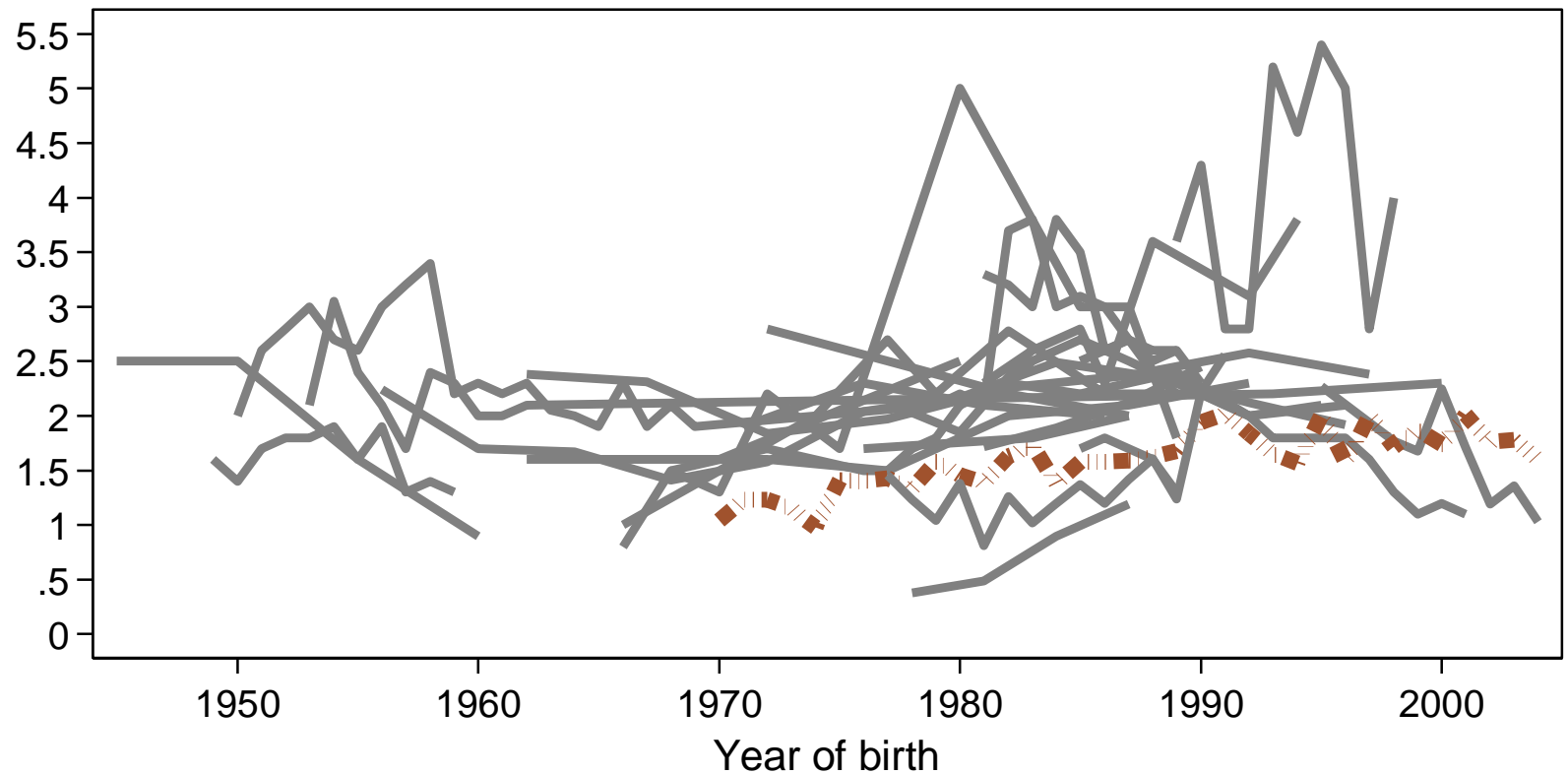




# But Total CP Rates in Victoria, 1970-2004: Stubbornly Steady.



# International Prevalence Rates



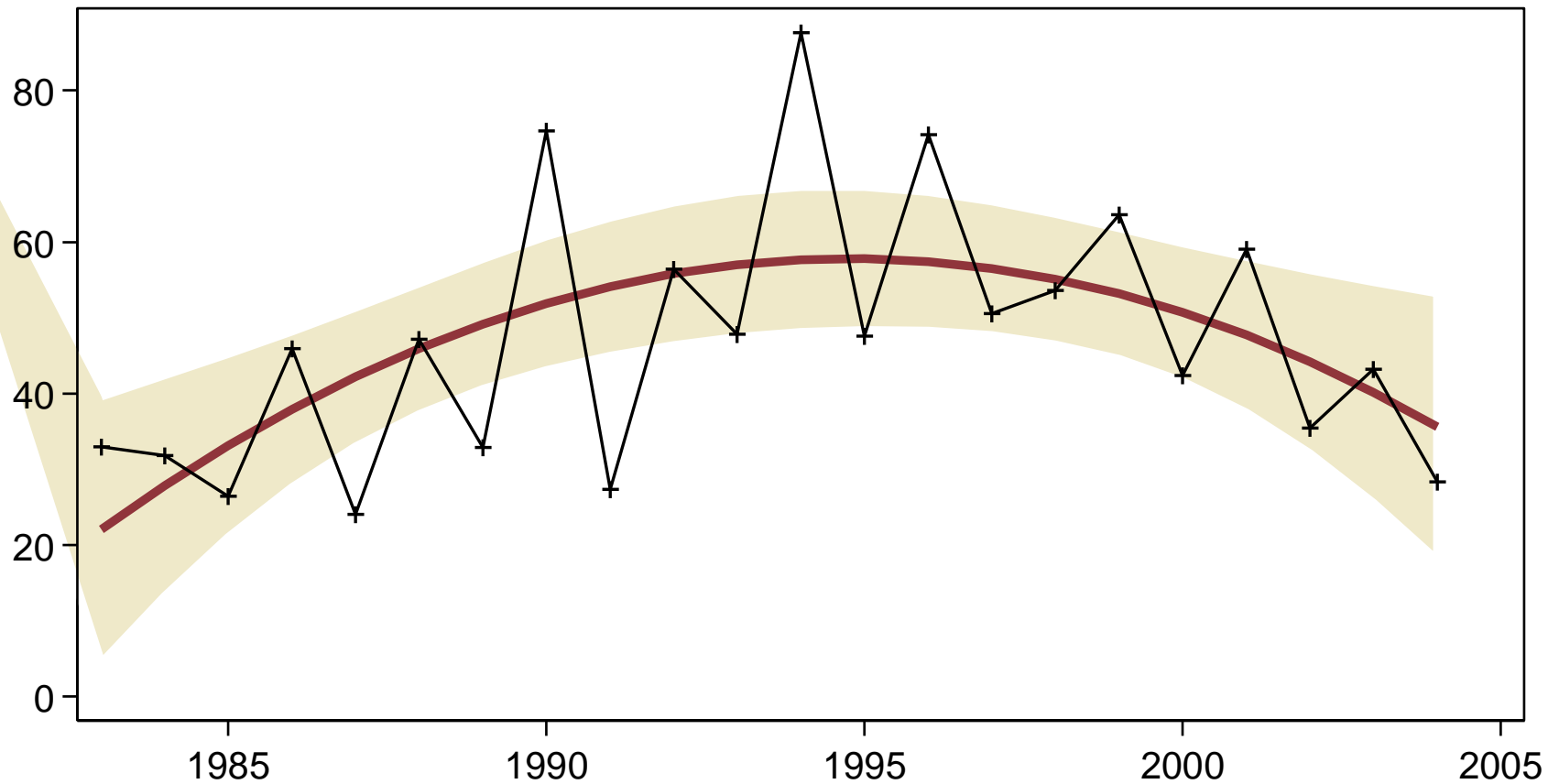
# Extremely Preterm Infants: Different

---

- **Extremely preterm births (20-27wks) have a higher risk of cerebral injury.**
- **The incidence of CP may be used to evaluate the effectiveness of neonatal intensive care.**



# Rate of CP/1000 LB, 20-27 wks, 1983-2004



# Epidemiological Summary

---

- **Rate of CP increased during 1980s and early 1990s**
- **Followed by a long plateau.**
- **Increased survival of extremely preterm infants**
- **Without a parallel improvement in neurological outcomes**
- **Increased CP rates for term births over same period**
- **Some evidence to suggest a reversal of this upward trend from mid-late 1990s**
- **Conclusions supported by other groups, including neonatal follow up studies in Victoria**

# Why is it so difficult to prevent CP?

---

- **No single cause: Complex causal pathways.**
- **Unitary causes, when identified are easily prevented.**
- **Eg Kernicterus, haemolytic disease, of newborn.**
- **Prematurity is very difficult to prevent.**
- **Some advances in maternal and neonatal health care reduce CP rates**
- **Other advances increase survival of VLBW babies**
- **Without reducing the rate of cerebral injury.**
- **CP is the many headed hydra.**

# Why is it so difficult to prevent CP?

---

## Management of infertility:

- Increased maternal age.
- Increase in multiple births: twins, triplets etc
- Increase in prematurity.
- Decrease in birth weight.
- Plus many 'unknown, unknowns'
- Increase in CP rates

# Cerebral Palsy: Access Economics

---

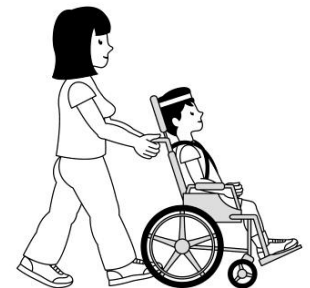
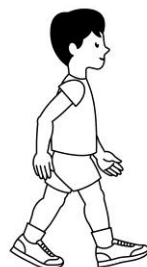
- 1. 1.8 per 1,000 births in Australia**
- 2. 62,000 live births p.a.**
- 3. 120 new cases p.a. in Victoria**
- 4. Most common cause of disability**
- 5. Most common diagnosis at RCH**
- 6. Most expensive condition to Rx**
- 7. Cost \$1.47 billion 2007, Aus.**
- 8. Prevalence steady**



# Have Wheelchair, Can Walk!

---

- 1. Communication.**
- 2. Independence.**
- 3. Mobility.**



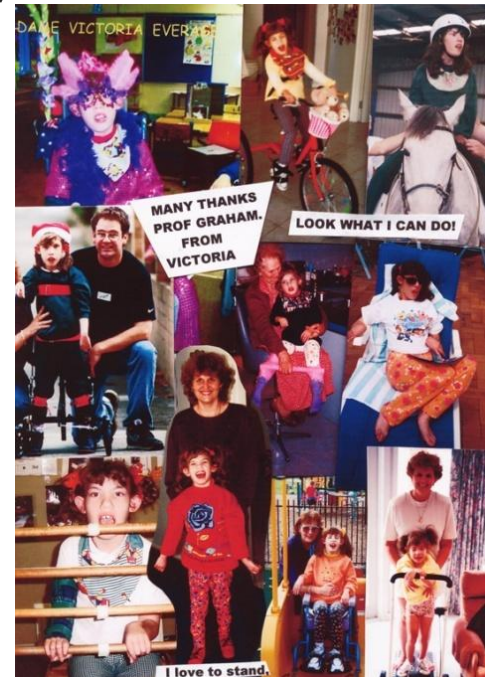
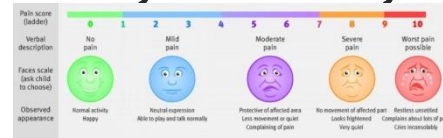
# The Victorian Cerebral Palsy Cohort Study: Birth Years: 1990-1992

---

- 1. 3 year inception cohort, from CP Register.**
- 2. GMFCS, Motor Types, *Howard, 2005, JPCH***
- 3. Hip Displacement: GMFCS, *Soo 2006, JBJS***
- 4. Transition to adult care study: *publish 2013***
- 5. Summarize history.**
- 6. Exit examination, radiology, questionnaires.**
- 7. Transition appointments: 2006 to 2012**

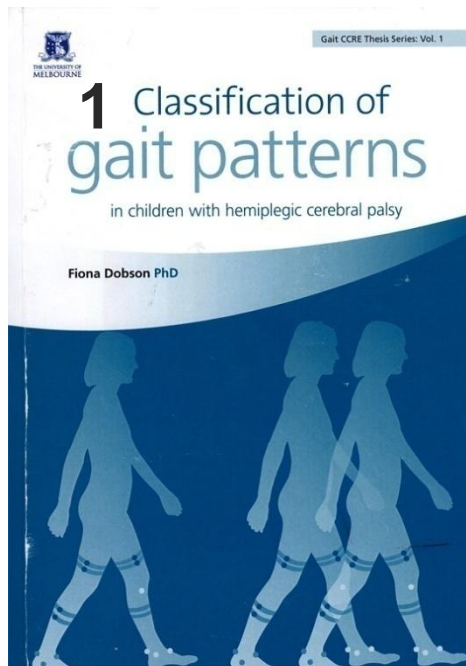
# Transition Clinic: Research Opportunity.

1. Review GMFCS, MACS, CFCS, MD, TD
2. Pain: several tools
3. Ambulant children: FMS, Gait, Hips, pain, contractures, deformities, CHQ
4. Non-ambulant Children: Hips, spine, pain, CP-Child
5. HRQOL questionnaires.
6. Photograph adolescents
7. Bring photos, stories, books...
8. It's Graduation Day!

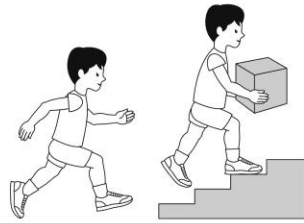


# The Victorian Cerebral Palsy Cohort Study: Birth Years: 1990-1992

1. Hemiplegia: Fiona Dobson PhD Studies
2. Diplegia: Gait Laboratory Records/TC
3. Quadriplegia: Ortho/Transition Clinic.

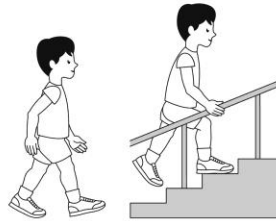


# GMFCS for children aged 6-12 years: Descriptors and illustrations



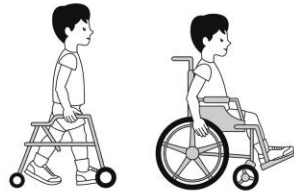
## GMFCS Level I

Children walk indoors and outdoors and climb stairs without limitation. Children perform gross motor skills including running and jumping, but speed, balance and coordination are impaired.



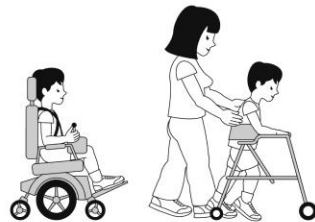
## GMFCS Level II

Children walk indoors and outdoors and climb stairs holding onto a railing but experience limitations walking on uneven surfaces and inclines and walking in crowds or confined spaces and with long distances.



## GMFCS Level III

Children walk indoors or outdoors on a level surface with an assistive mobility device and may climb stairs holding onto a railing. Children may use wheelchair mobility when traveling for long distances or outdoors on uneven terrain.



## GMFCS Level IV

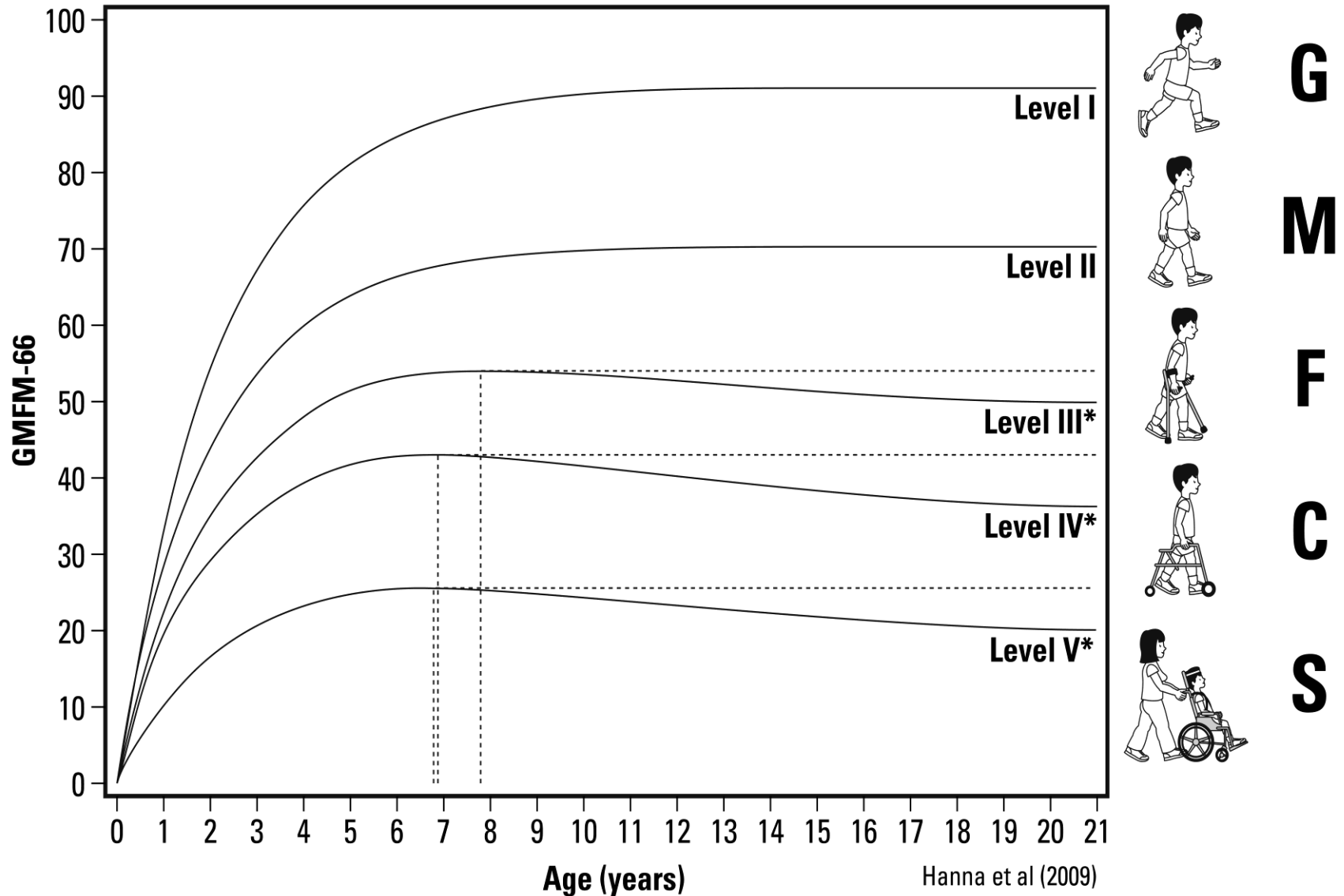
Children use methods of mobility that usually require adult assistance. They may continue to walk for short distances with physical assistance at home but rely more on wheeled mobility (pushed by an adult or operate a powered chair) outdoors, at school and in the community.



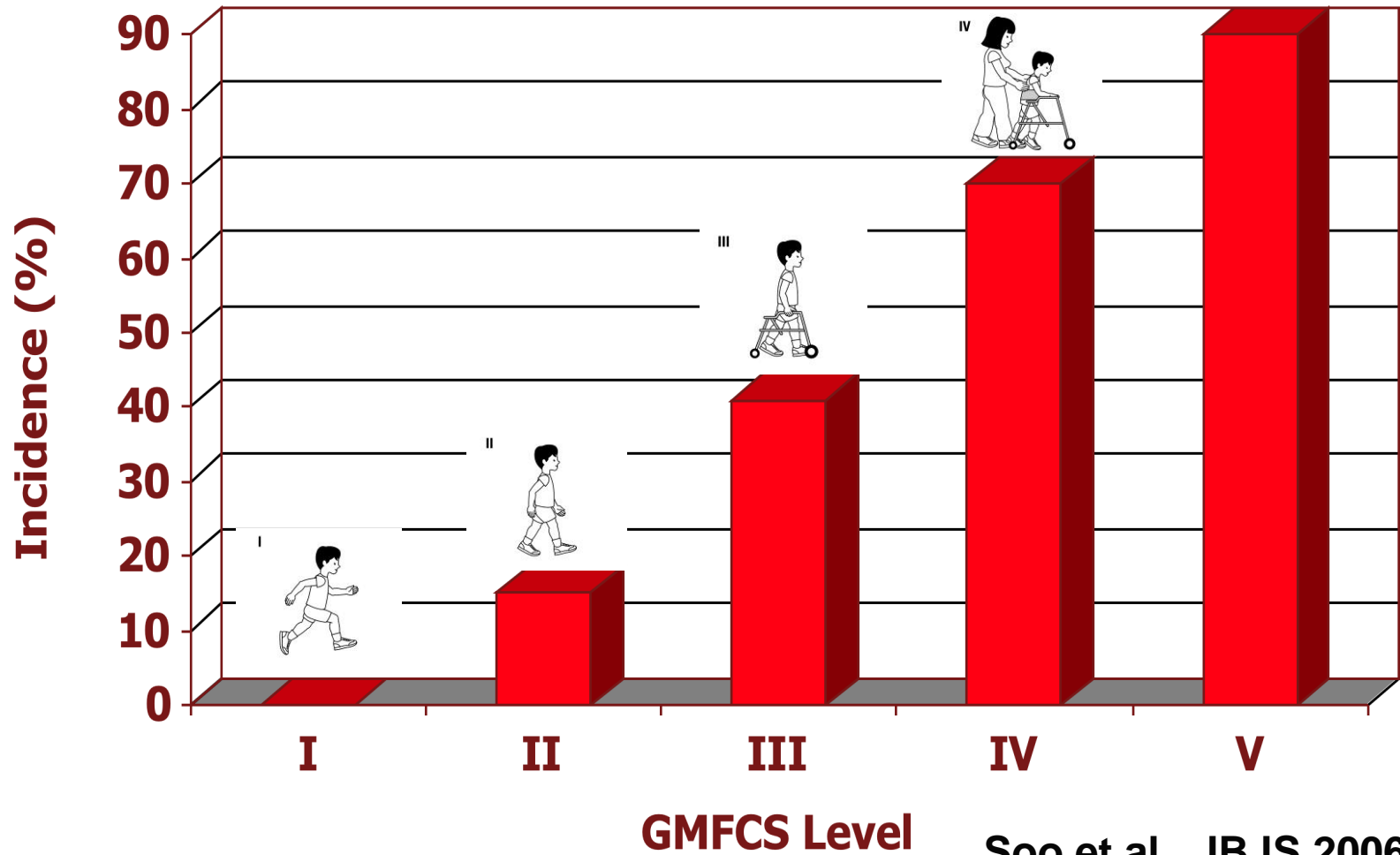
## GMFCS Level V

Physical impairment restricts voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Children have no means of independent mobility and are transported by an adult.

# Gross Motor Curves in Cerebral Palsy



# Hip Displacement (MP>30%) & GMFCS



Soo et al., JBJS 2006

# GMFCS in Cerebral Palsy

---

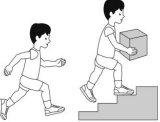
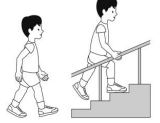
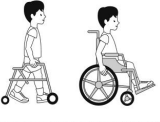


1. Predicts long term gross motor function.
2. Valid, reliable and stable. (relatively)
3. Can be used by parents, therapists, MDs.
4. Predicts co-morbidities and mortality.
5. Perfect context to set management goals.
6. Predicts success of operative procedures.
7. **Key communication tool.**
8. **Key epidemiological tool.**
9. **Pre-requisite for all CP publications.**



# 3 Tools: GMFCS, MACS and CFCS.

## Gross Motor Function    Upper Limb Function    Communication Function

### GMFCS for children aged 6-12 years: Descriptors and illustrations

	<p><b>GMFCS Level I</b></p> <p>Children walk indoors and outdoors and climb stairs without limitation. Children perform gross motor skills including running and jumping, but speed, balance and coordination are impaired.</p>
	<p><b>GMFCS Level II</b></p> <p>Children walk indoors and outdoors and climb stairs holding onto a railing but experience limitations walking on uneven surfaces and inclines and walking in crowds or confined spaces and with long distances.</p>
	<p><b>GMFCS Level III</b></p> <p>Children walk indoors or outdoors on a level surface with an assistive mobility device and may climb stairs holding onto a railing. Children may use wheelchair mobility when traveling for long distances or outdoors on uneven terrain.</p>
	<p><b>GMFCS Level IV</b></p> <p>Children use methods of mobility that usually require adult assistance. They may continue to walk for short distances with physical assistance at home but rely more on wheeled mobility (pushed by an adult or operate a powered chair) outdoors, at school and in the community.</p>
	<p><b>GMFCS Level V</b></p> <p>Physical impairment restricts voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Children have no means of independent mobility and are transported by an adult.</p>

Illustrations copyright © Kerry Graham, Bill Reid and Adrienne Harvey, The Royal Children's Hospital, Melbourne. CRC, 012028



### Manual Ability Classification System for Children with Cerebral Palsy 4-18 years

MACS classifies how children with cerebral palsy use their hands to handle objects in daily activities.

- MACS describes how children usually use their hands to handle objects in the home, school, and community settings (what they do), rather than what is known to be their best capacity.
- In order to obtain knowledge about how a child handles various everyday objects, it is necessary to ask someone who knows the child well, rather than through a specific test.
- The objects the child handles should be considered from an age-related perspective.
- MACS classify a child's overall ability to handle objects, not each hand separately.

2005, updated 2010

### Communication Function Classification System (CFCS) for Individuals with Cerebral Palsy

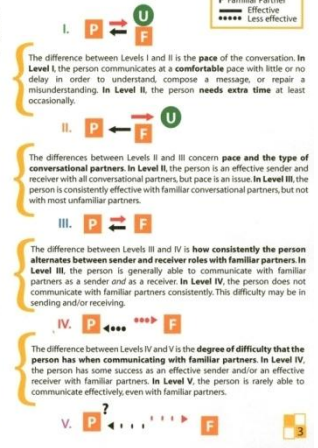
**Effective Sender and Receiver with unfamiliar and familiar partners.** The person independently alternates between sender and receiver roles with most people in most environments. The communication occurs easily and at a comfortable pace with both unfamiliar and familiar conversational partners. Communication misunderstandings are quickly repaired and do not interfere with the overall effectiveness of the person's communication.

**Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners.** The person independently alternates between sender and receiver roles with most people in most environments, but the conversational pace is slow and may make the communication interaction more difficult. The person may need extra time to understand messages, compose messages, and/or repair misunderstandings. Communication misunderstandings are often repaired and do not interfere with the eventual effectiveness of the person's communication with both unfamiliar and familiar partners.

**Effective Sender and Receiver with familiar partners.** The person alternates between sender and receiver roles with familiar (but not unfamiliar) conversational partners in most environments. Communication is not consistently effective with most unfamiliar partners, but is usually effective with familiar partners.

**Inconsistent Sender and/or Receiver with familiar partners.** The person does not consistently alternate sender and receiver roles. This type of inconsistency might be seen in different types of communicators including: a) an occasionally effective sender and receiver; b) an effective sender but limited receiver; c) a limited sender but effective receiver. Communication is sometimes effective with familiar partners.

**Seldom Effective Sender and Receiver even with familiar partners.** The person is limited as both a sender and a receiver. The person's communication is difficult for most people to understand. The person appears to have limited understanding of messages from most people. Communication is seldom effective even with familiar partners.



# The Victorian Cerebral Palsy Cohort Study: Birth Years: 1990-1992

---

- Birth cohort N = 374 (Predicted = 360)
- 2005 reported on 323 (86%)
- 2013 will report n =292 (78%) 170 Male, 122 female
- Majority: MRI: 3 excluded (2 HSP, 1 Metabolic)
- GMFCS Stable 91% unchanged
- Topographical Distribution Stable 97% unchanged
- Movement disorder showed major changes.
- Mortality, by mean age 22 years = 38, 12%
- GMFCS, mortality, respiratory disease and scoliosis.

# The Victorian Cerebral Palsy Cohort Study: Birth Years: 1990-1992

---

## Movement Disorder 2005

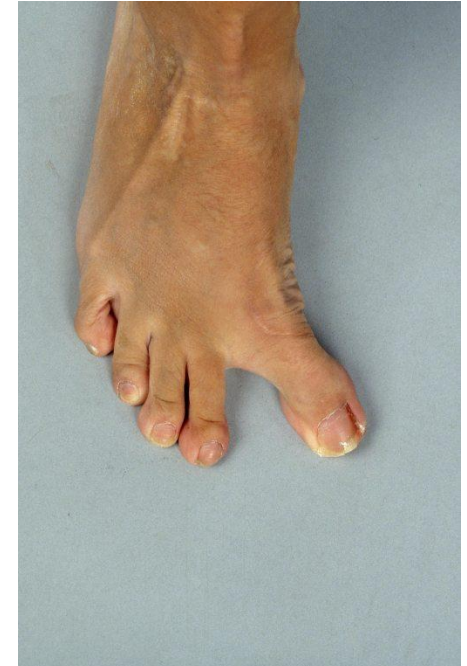
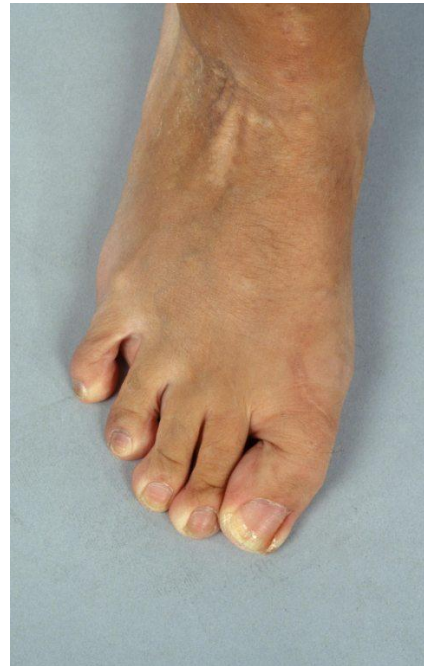
- Spastic 86%
- Mixed Hypertonia 7%
- Dyskinetic 2%
- Ataxia 3%
- Hypotonia 3%

## Movement Disorder 2012

- Spastic 53%
- Mixed hypertonia 33%
- Dyskinetic 11%
- Ataxia 3%

# The Victorian Cerebral Palsy Cohort Study: Birth Years: 1990-1992

**Mixed Hypertonia: Previously “Spastic Quadriplegia”  
Spastic and Dystonic Features (Fingers and Toes)**



# The Victorian Cerebral Palsy Cohort Study: Hemiplegia Summary.

---

- 1. Single level surgery for equinus/varus.**
- 2. Recurrence/relapse reduced by Botox**
- 3. Botox + OT Upper limb**
- 4. Upper limb surgery: limited numbers**
- 5. Hip disease: only Type IV hemiplgia**
- 6. Mild scoliosis: common**
- 7. Severe scoliosis (requiring surgery) in 1 teenager with dystonia.**
- 8. Only one death, to date.**

# The Victorian Cerebral Palsy Cohort Study: Diplegia Summary

---

- 1. Sagittal gait patterns classified.**
- 2. Crouch gait: greatly reduced.**
- 3. SEMLS RCT: Pam Thomason**
- 4. 50% improvement in Gait**
- 5. 5% improvement in GMFM**
- 6. GMFCS stable or improved in 5%**
- 7. Hip disease: mild, easily treated**
- 8. Scoliosis: mild, non progressive**
- 9. 2 deaths, to date: MVA, drowning**

# The Victorian Cerebral Palsy Cohort Study: Quadriplegia Summary

---

- **Spastic Quadriplegia: Whole Body**
- **Multiple Medical Co-morbidities**
- **Severe hypertonia**
- **90%: hip displacement & scoliosis**
- **Child and Care giver QoL**
- **Realistic goals: comfortable sitting**
- **Communication and participation**
- **40% mortality at age 22 years**



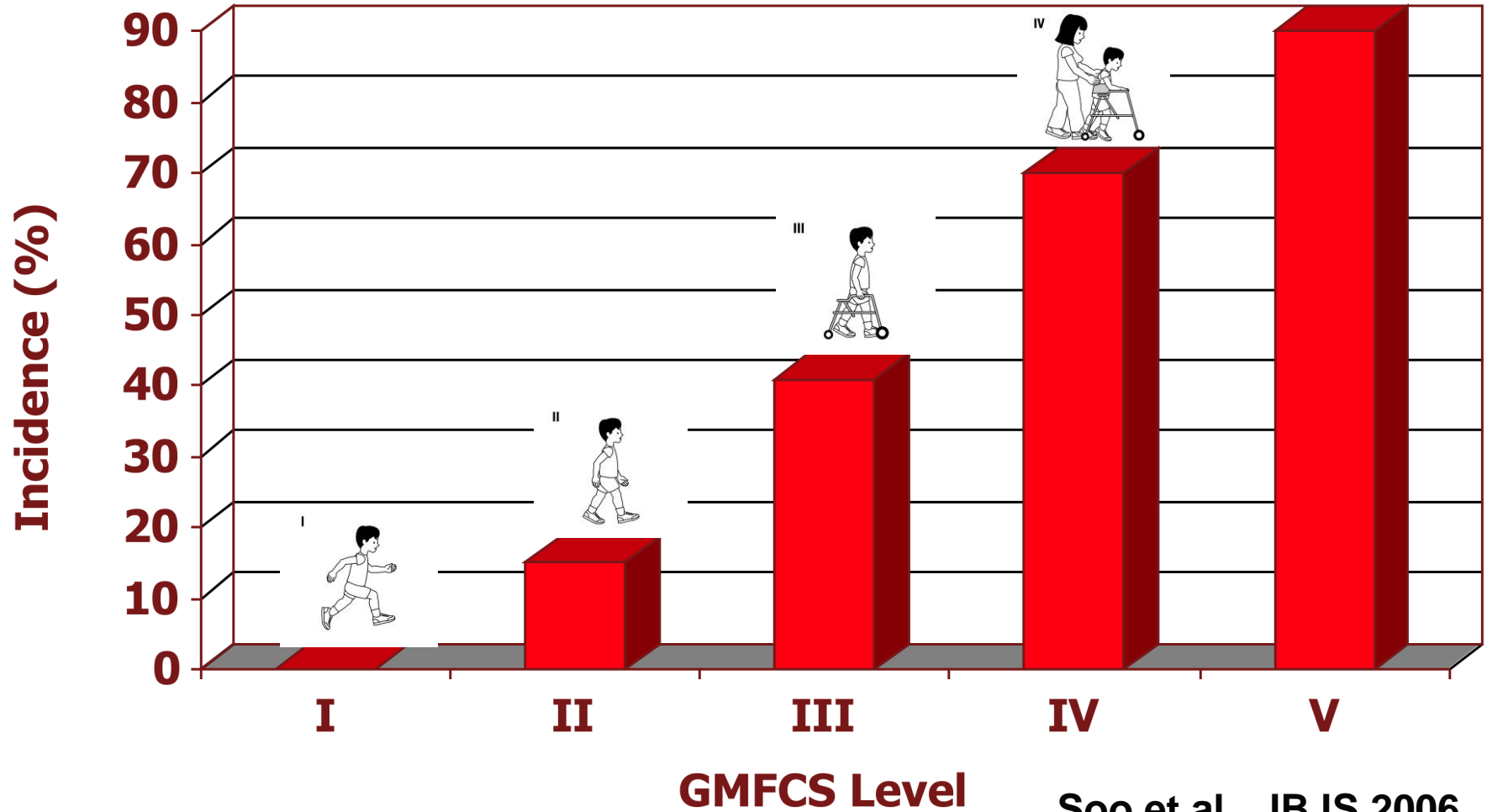
# GMFCS Level IV and V



- **Survival: All causes, mortality.**
- **Medical co-morbidities.**
- **Pain prevalence.**
- **Sitting ability.**
- **Hips.**
- **Spine: scoliosis.**
- **HRQoL: CPCHILD**



# Hip Displacement (MP>30%) & GMFCS



Soo et al., JBJS 2006

# A tale of two siblings.

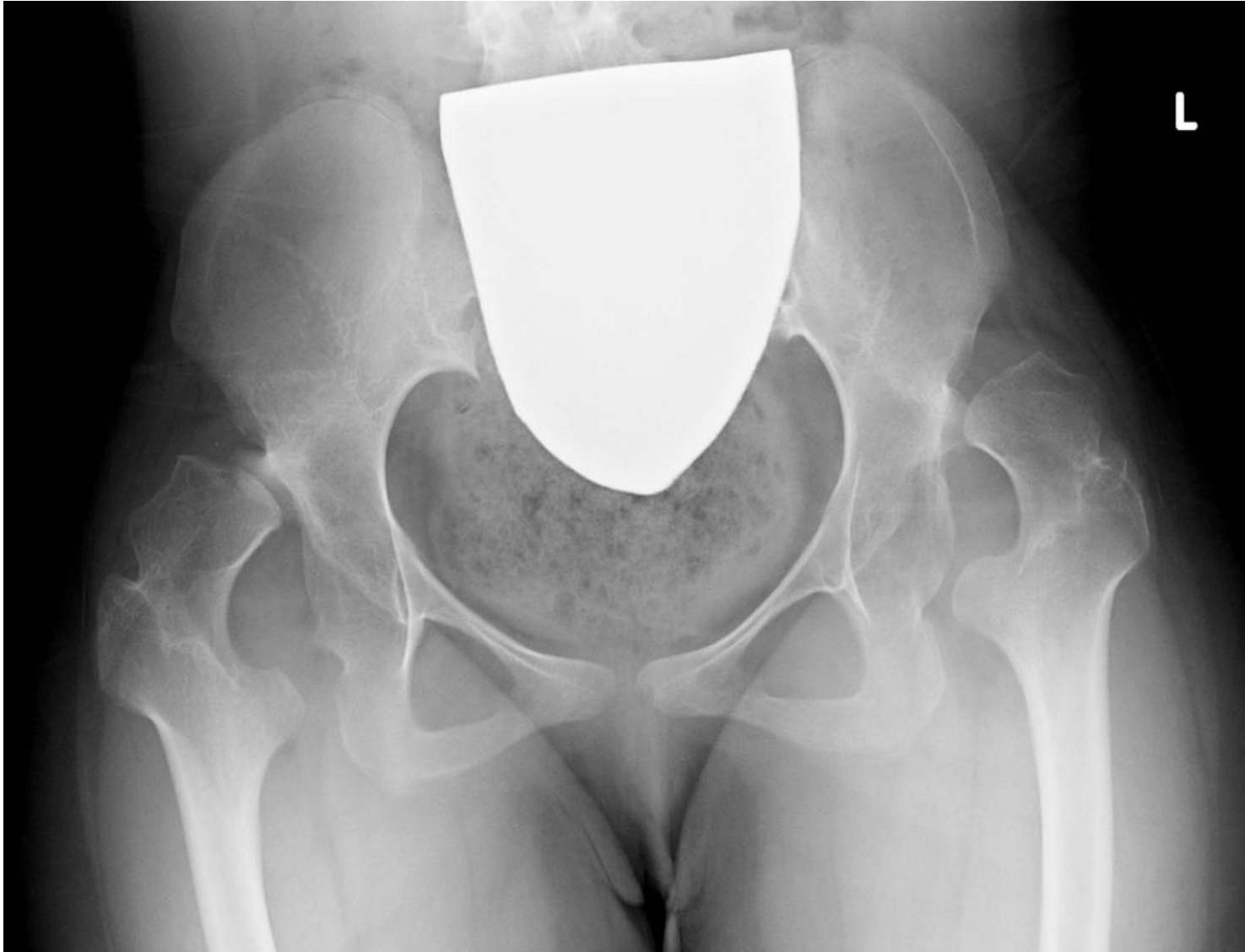


# A tale of two siblings.

---



# A's Hips 14 years: Pain, ADLs

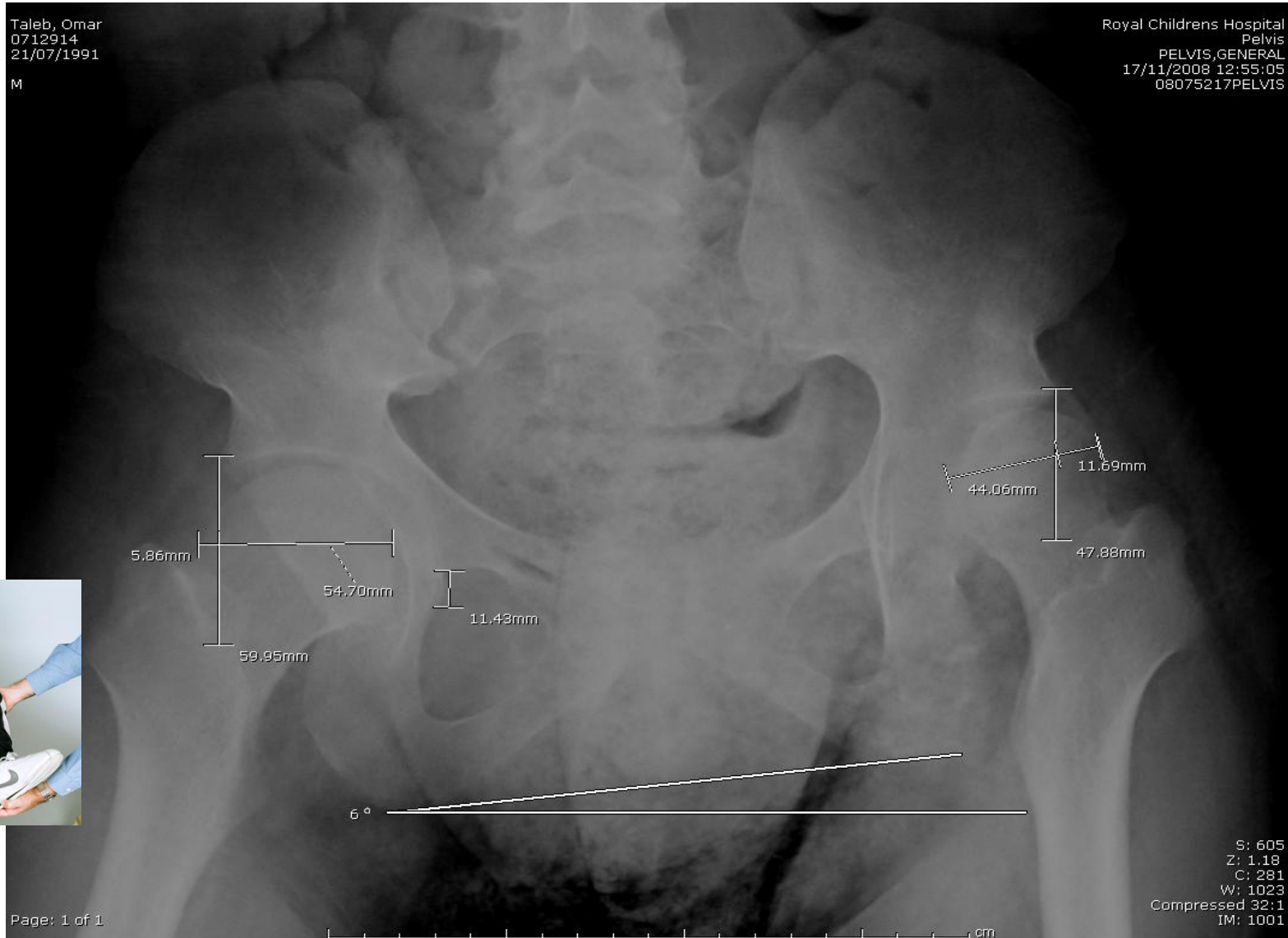


# B's Hips 16 years: No Pain No disability: sitting time, ADLs

Taleb, Omar  
0712914  
21/07/1991

M

Royal Childrens Hospital  
Pelvis  
PELVIS, GENERAL  
17/11/2008 12:55:05  
08075217PELVIS





## GMFCS Level IV



1. Age 3+2, CP-Severe ID, migrants.
2. Non verbal, non ambulant.
3. MPs 25% Left, 45% Right
4. Adductor surgery.
5. Lost to follow up.





# GMFCS Level IV



1. B at 16 years.
2. Mobile, pain free, hips;
3. Adductor releases age 4 years.
4. 12 year follow up.





# GMFCS Level IV

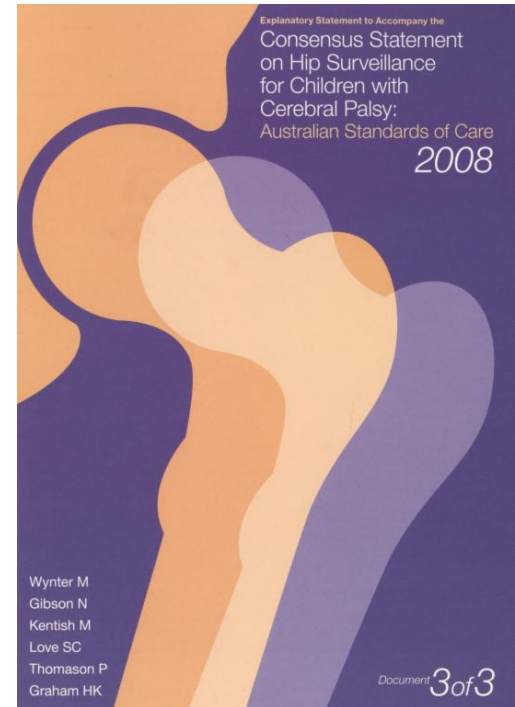
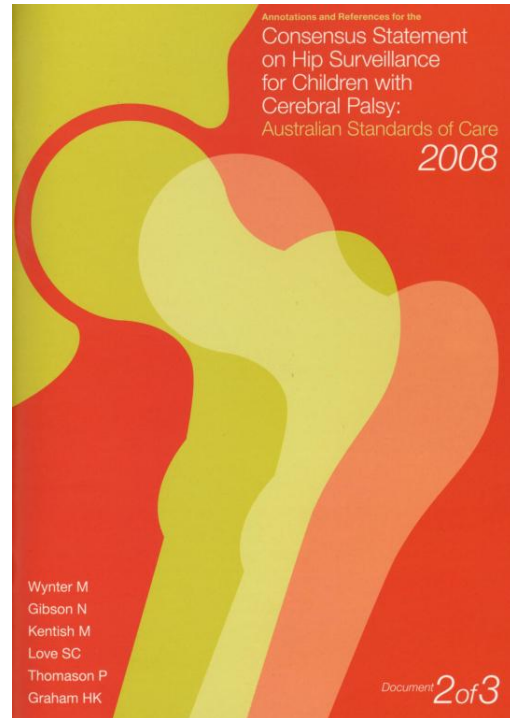
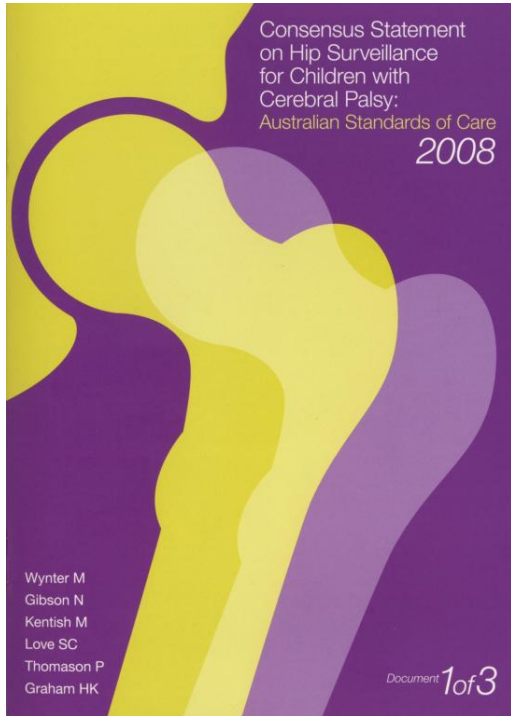


**Salvage surgery: not successful**





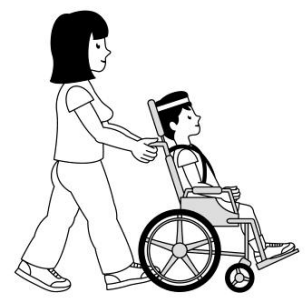
# Consensus Statement on Hip Surveillance for Children with Cerebral Palsy.



# Hip Surveillance for Children with CP.

- Clinical and radiographic screening.
- By Physiotherapists and surgeons
- Early detection.
- Early intervention
- Prevents dislocation
- Avoids salvage surgery





# GMFCS, Mortality and Scoliosis

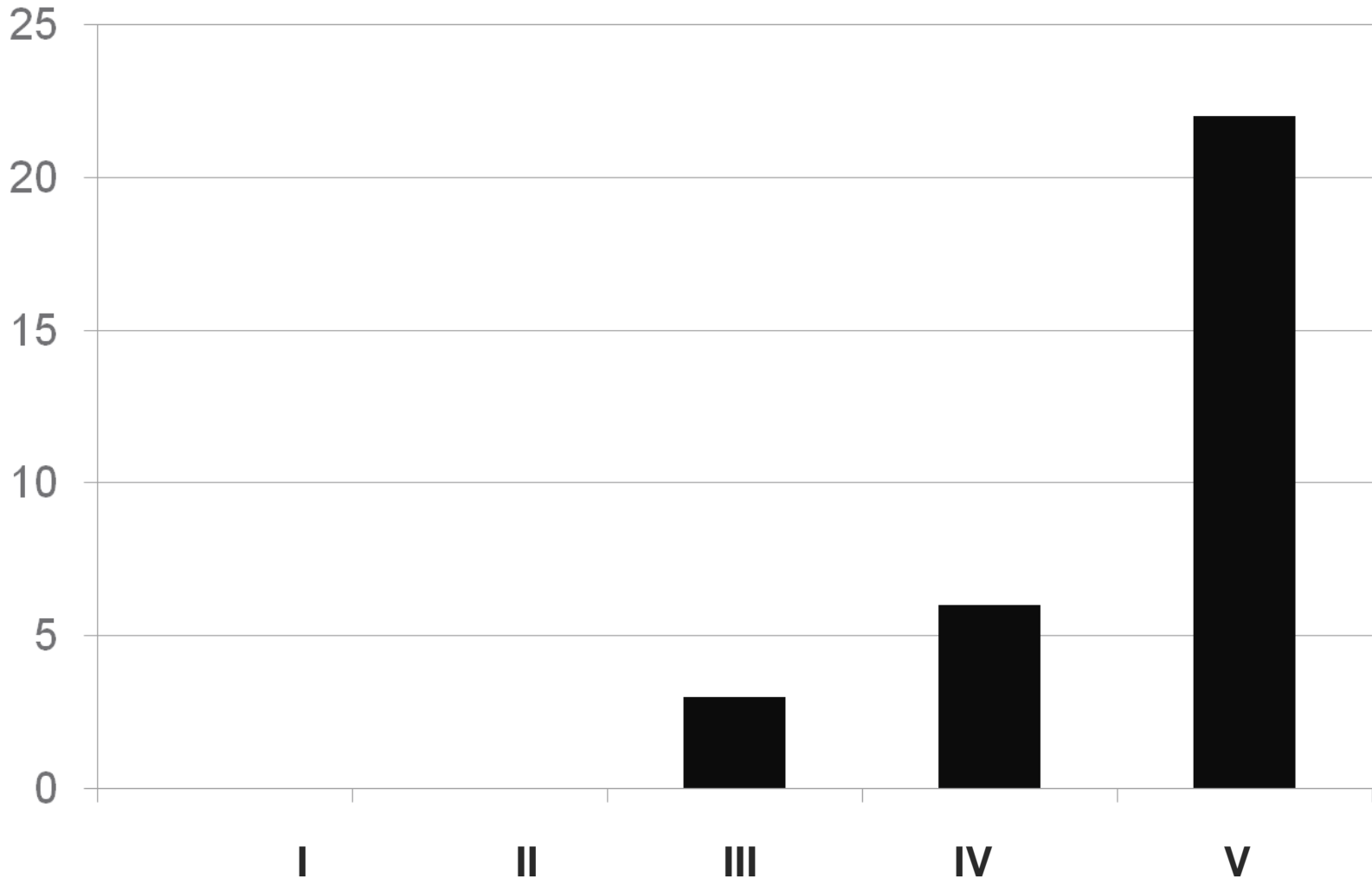
---

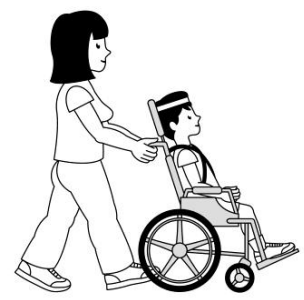
- 1. N=31(10%), by age 22 years**
- 2. Cause of death**
- 3. GMFCS**
- 4. MACS**
- 5. Scoliosis**



# Mortality and GMFCS

**N=31(10%) whole population, by age 22**

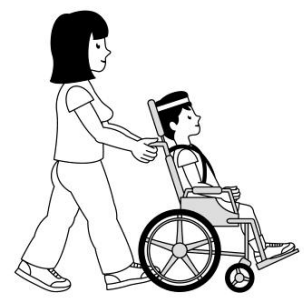




# Mortality and GMFCS; N=31

---

- 1. GMFCS I**      **0/93 = 0%**
- 2. GMFCS II**      **0/46 = 0%**
- 3. GMFCS III**      **3/43 = 7%**
- 4. GMFCS IV**      **6/51 = 12%**
- 5. GMFCS V**      **22/56 = 39%**



## Cause of Death; N=31

---

- 1. Respiratory = 21**
- 2. Cardiac/respiratory = 2**
- 3. Epilepsy = 2; Epilepsy surgery = 1**
- 4. Septicaemia = 1**
- 5. MVA = 1**
- 6. Drowning = 1**
- 7. Unknown = 4**

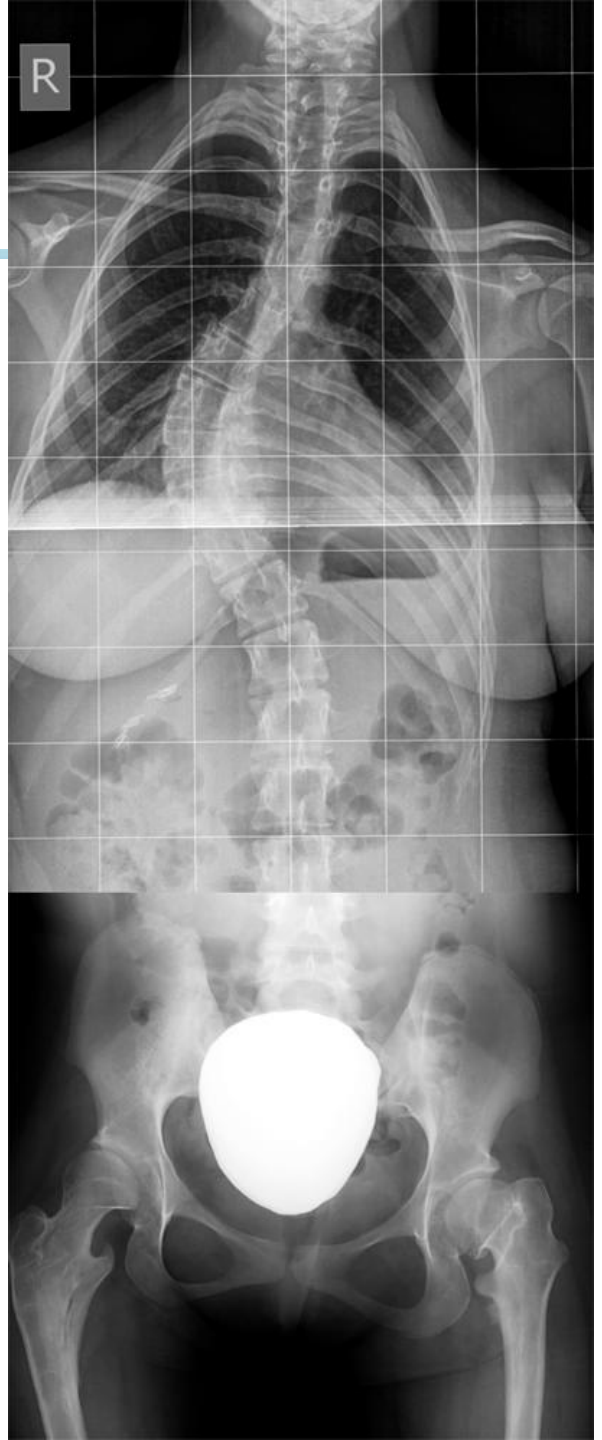
# KS, Age 21, GMFCS III MACS I, CFCS I



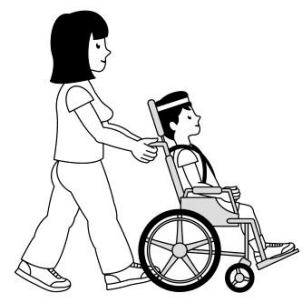
# SD: Age 20, GMFCS IV



**Hypotonia: now Mixed Hypertonia**  
**GMFCS IV: Stable**  
**MACS II**  
**CFCS I tweets, blogs and e mails**







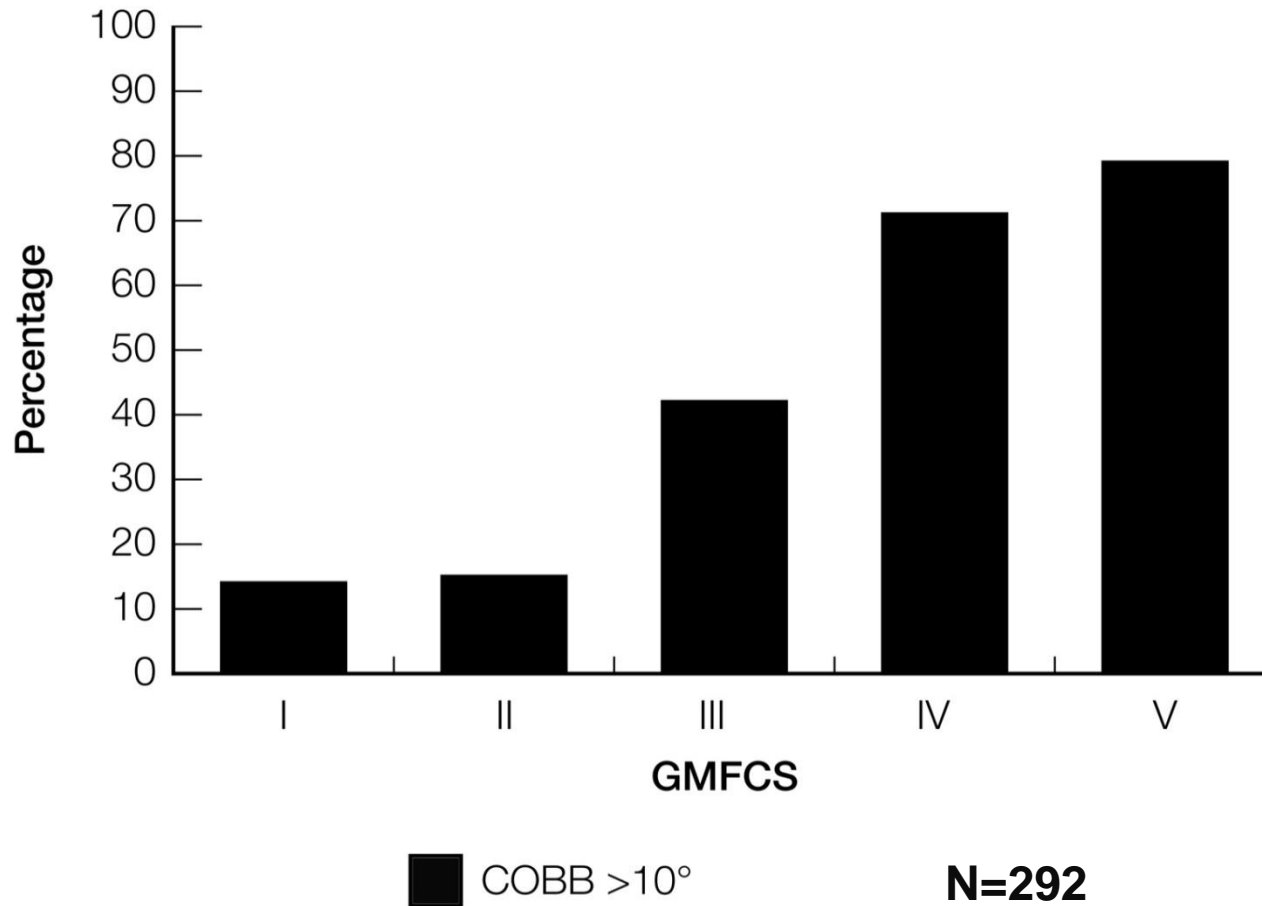
# AS Age 21 GMFCS V, MACS V, CFCS V.

---



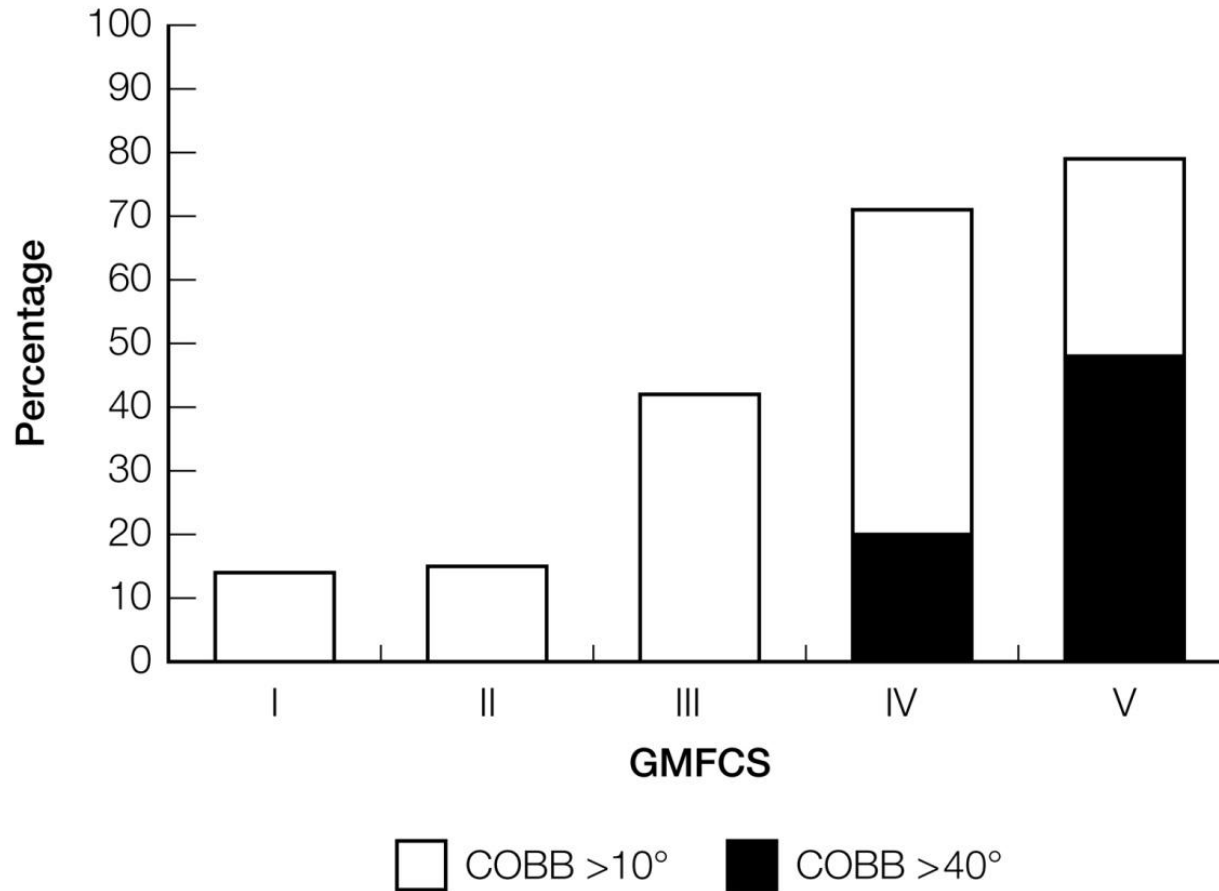
# GMFCS & Scoliosis: Cobb >10°

## Scoliosis in Cerebral Palsy



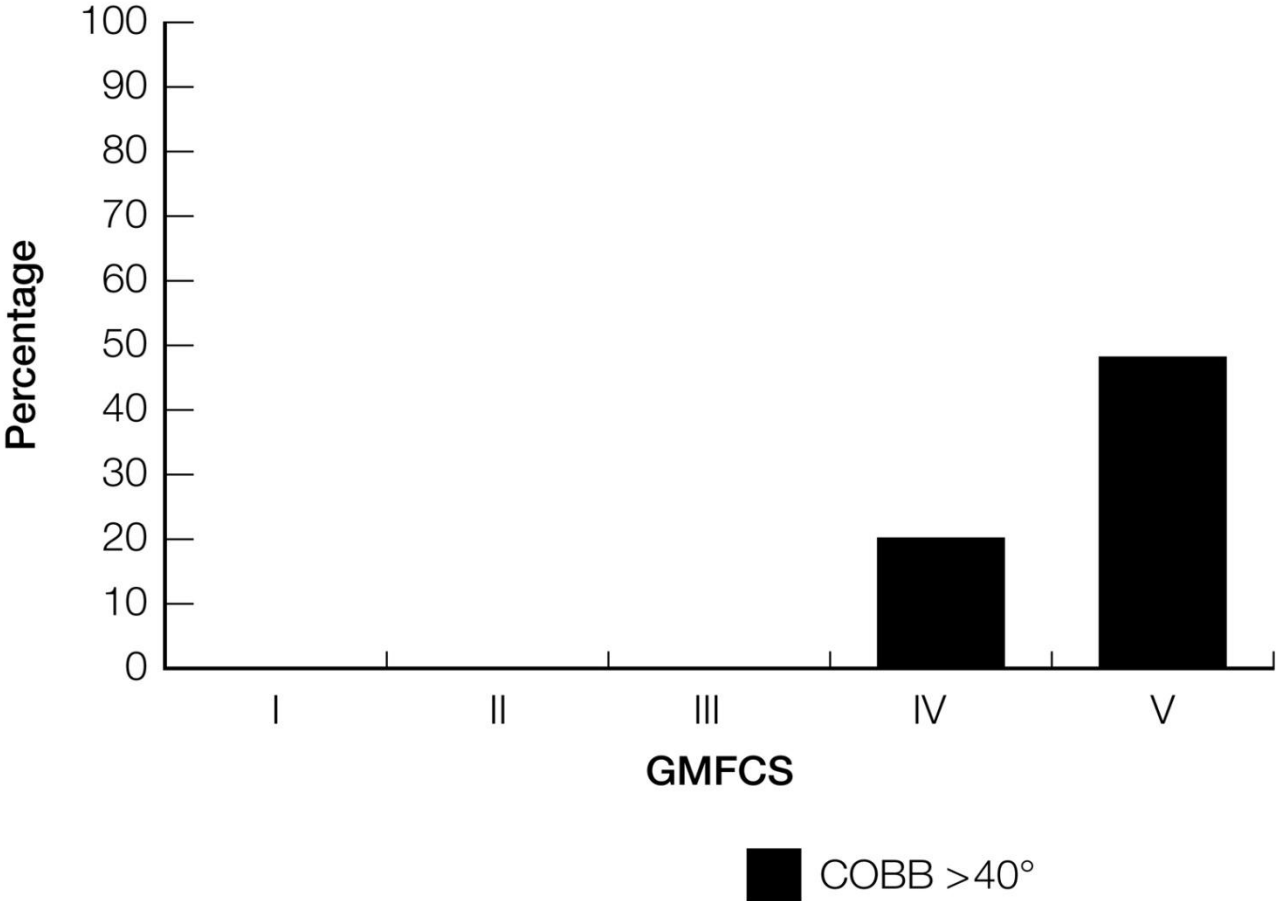
# Clinically Significant Scoliosis > 40°

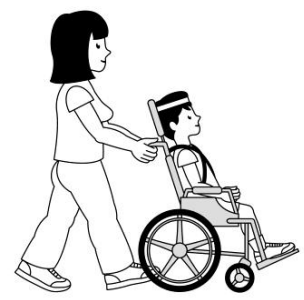
Scoliosis in Cerebral Palsy



# Clinically Significant Scoliosis > 40°

Scoliosis in Cerebral Palsy



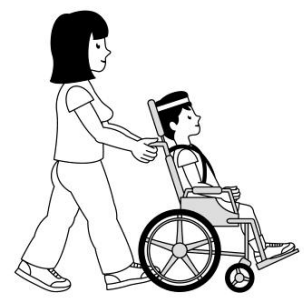


# Mortality and Scoliosis

---

1. Cobb  $< 10 = 10$
2. Cobb 10-20 = 3
3. Cobb 20-40 = 4
4. **Cobb  $> 40 = 14$**

**68% of Deaths were in Children with Scoliosis**



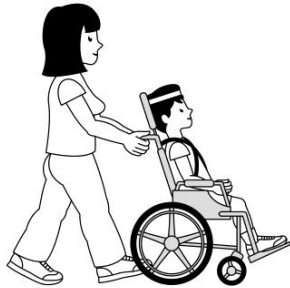
# Mortality and Scoliosis

---

1. N=31 = 10%, by age 22
2. Respiratory = 20
3. Scoliosis > 40 = 14
4. MACS V = 18
5. GMFCS V = 22

**Profile for premature mortality <20 years was:  
GMFCS V, MACS V, CFCS V, a feeding tube,  
respiratory disease, hip disease and early  
onset scoliosis.**

# Poor Function - Excellent QoL



## Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child)



The CP QOL-Child is suitable for children aged 4- 12 years

- The CP QOL-Child measures:
- > Social wellbeing and acceptance
  - > Functioning
  - > Participation and physical health
  - > Emotional wellbeing
  - > Access to services
  - > Pain and impact of disability
  - > Family health

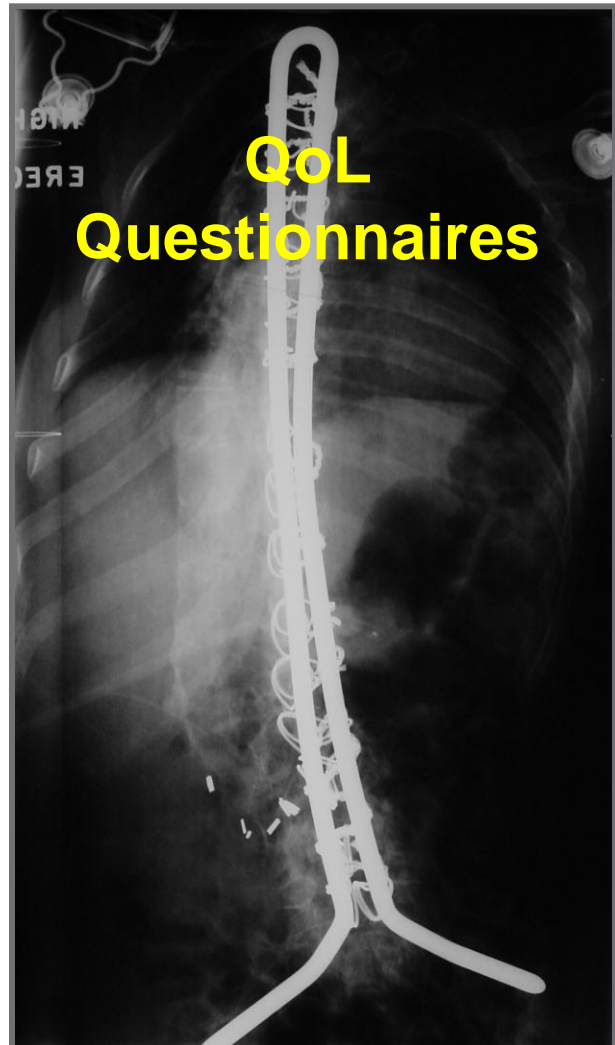
If you would like to use the CP QOL-Child or would like more information, please contact:

> **Professor Elizabeth Waters**  
elizabeth.waters@deakin.edu.au  
03 9251-7265

OR

> **Dr Elise Davis**  
elise.davis@deakin.edu.au  
03 9244-6131


Professor Elizabeth Waters, Dr Elise Davis, A/Professor Dinah Reddihough, Professor H. Kerr Graham, Professor Andrew Mackinnon, Dr Rory Wolfe, A/Professor Richard Stevenson, Ms Kristie Bjornson, A/Professor Eve Blair, Dr Peter Hoare, Professor Ulrike Ravens-Sieberer, Dr Roslyn Boyd



# Quality of Life in Cerebral Palsy.

1. **All children: Generic: PedsQL.**
2. **All Children with CP: CP QoLChild**
3. **GMFCS IV/V Specific (Toronto):CP CHILD**

**Cerebral Palsy  
Quality of Life Questionnaire  
for Children**  
(CP QOL-Child)



The CP QOL-Child is suitable for children aged 4-12 years

The CP QOL-Child measures:

- > Social wellbeing and acceptance
- > Functioning
- > Participation and physical health
- > Emotional wellbeing
- > Access to services
- > Pain and impact of disability
- > Family health

If you would like to use the CP QOL-Child or would like more information, please contact:

> **Professor Elizabeth Waters**  
elizabeth.waters@deakin.edu.au  
03 9251-7265

OR

> **Dr Elise Davis**  
elise.davis@deakin.edu.au  
03 9244-6131

Professor Elizabeth Waters, Dr Elise Davis, A/Professor Dinah Reddkhough, Professor H. Ken Graham, Professor Andrew Mackinnon, Dr Rory Wolfe, A/Professor Richard Stevenson, Ms Kristie Bjornson, A/Professor Eve Blair, Dr Peter Hoare, Professor Ulrike Ravens-Sieberer, Dr Roslyn Boyd

**Care giver  
Priorities and  
Child  
Health  
Index of  
Life with  
Disabilities.**






# Quality of Life in Cerebral Palsy.

1. All children: Generic: PedsQL.
2. All Children with CP: CP QoLChild (Melb)
3. GMFCS IV/V Specific (Toronto):CP CHILD

**Cerebral Palsy  
Quality of Life Questionnaire  
for Children**  
(CP QOL-Child)



The CP QOL-Child is suitable for children aged 4-12 years

The CP QOL-Child measures:

- > Social wellbeing and acceptance
- > Functioning
- > Participation and physical health
- > Emotional wellbeing
- > Access to services
- > Pain and impact of disability
- > Family health

If you would like to use the CP QOL-Child or would like more information, please contact:

> **Professor Elizabeth Waters**  
elizabeth.waters@deakin.edu.au  
03 9251-7265

OR

> **Dr Elise Davis**  
elise.davis@deakin.edu.au  
03 9244-6131

Professor Elizabeth Waters, Dr Elise Davis, A/Professor Dinah Reddkhough, Professor H. Ken Graham, Professor Andrew Mackinnon, Dr Rory Wolfe, A/Professor Richard Stevenson, Ms Kristie Bjornson, A/Professor Eve Blair, Dr Peter Hoare, Professor Ulrike Ravens-Sieberer, Dr Roslyn Boyd


**Care giver  
Priorities and  
Child  
Health  
Index of  
Life with  
Disabilities.**



# Quality of Life in Cerebral Palsy.

1. All children: Generic: PedsQL.
2. All Children with CP: CP QoLChild
3. **GMFCS IV/V Specific (Toronto):CP CHILD**

**Cerebral Palsy  
Quality of Life Questionnaire  
for Children**  
(CP QOL-Child)



The CP QOL-Child is suitable for children aged 4-12 years

The CP QOL-Child measures:

- > Social wellbeing and acceptance
- > Functioning
- > Participation and physical health
- > Emotional wellbeing
- > Access to services
- > Pain and impact of disability
- > Family health

If you would like to use the CP QOL-Child or would like more information, please contact:

> **Professor Elizabeth Waters**  
elizabeth.waters@deakin.edu.au  
03 9251-7265

OR

> **Dr Elise Davis**  
elise.davis@deakin.edu.au  
03 9244-6131

Professor Elizabeth Waters, Dr Elise Davis, A/Professor Dinah Reddkhough, Professor H. Ken Graham, Professor Andrew Mackinnon, Dr Rory Wolfe, A/Professor Richard Stevenson, Ms Kristie Bjornson, A/Professor Eve Blair, Dr Peter Hoare, Professor Ulrike Ravens-Sieberer, Dr Roslyn Boyd

**Care giver  
Priorities and  
Child  
Health  
Index of  
Life with  
Disabilities.**



# Quality of Life in Cerebral Palsy: Review of n=20 articles.

---

- 1. Individuals with CP have reduced QoL and HRQoL in some (not all) areas.**
- 2. QoL and HRQoL: do not correlate with function.**
- 3. Important differences by age.**
- 4. And GMFCS level.**

# Quality of Life in Cerebral Palsy.

## GMFCS I-V

## GMFCS IV and V

### Cerebral Palsy Quality of Life Questionnaire for Children

(CP QOL-Child)



The CP QOL-Child is suitable for children aged 4- 12 years

The CP QOL-Child measures:

- > Social wellbeing and acceptance
- > Functioning
- > Participation and physical health
- > Emotional wellbeing
- > Access to services
- > Pain and impact of disability
- > Family health

If you would like to use the CP QOL-Child or would like more information, please contact:

> **Professor Elizabeth Waters**  
elizabeth.waters@deakin.edu.au  
03 9251-7265

OR

> **Dr Elise Davis**  
elise.davis@deakin.edu.au  
03 9244-6131

# Care giver Priorities and Child Health Index of Life with Disabilities.

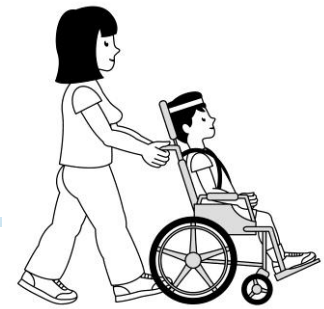
Professor Elizabeth Waters, Dr Elise Davis, A/Professor Dinah Reddihough, Professor H. Kerr Graham, Professor Andrew Mackinnon, Dr Rory Wolfe, A/Professor Richard Stevenson, Ms Kristie Bjornson, A/Professor Eve Blair, Dr Peter Hoare, Professor Ulrike Ravens-Sieberer, Dr Roslyn Boyd





## GMFCS Level V

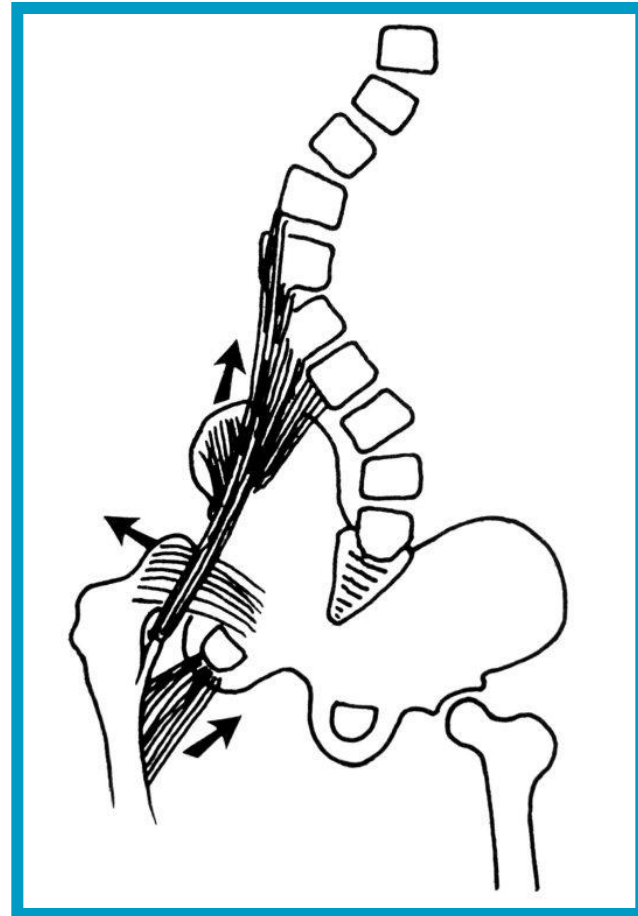
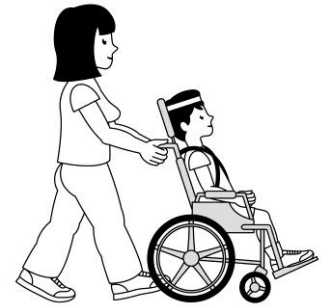
---

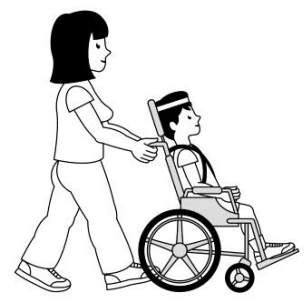


- **Spastic Quadriplegia: Whole Body**
- **Multiple Medical Co-morbidities**
- **Severe hypertonia**
- **90%: hip displacement & scoliosis**
- **Child and Care giver QoL**
- **Realistic goals: comfortable sitting**
- **Communication and participation**
- **40% mortality at age 22 years**



# Loss of sitting ability



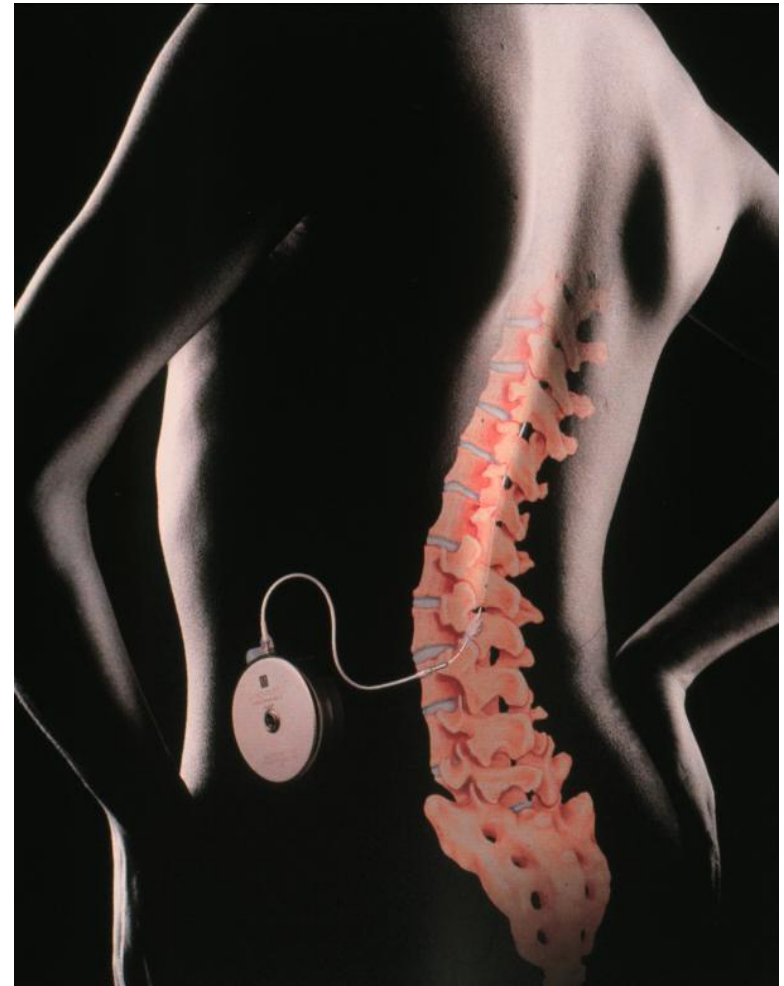
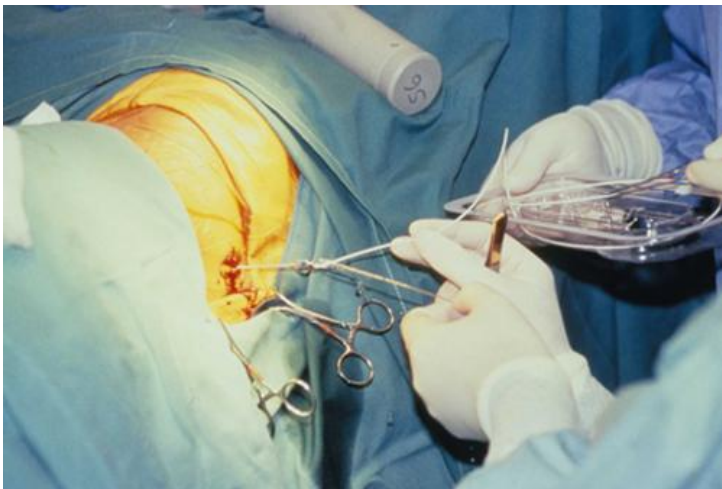
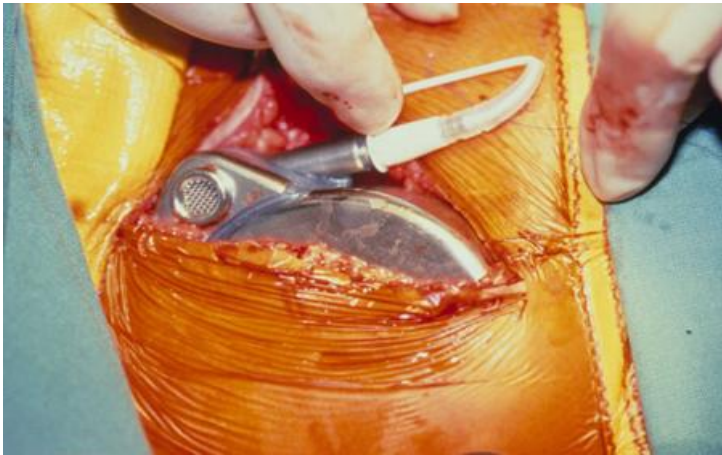


# AS Age 21 GMFCS V, MACS V, CFCS V.

---



# Intrathecal Baclofen(ITB)



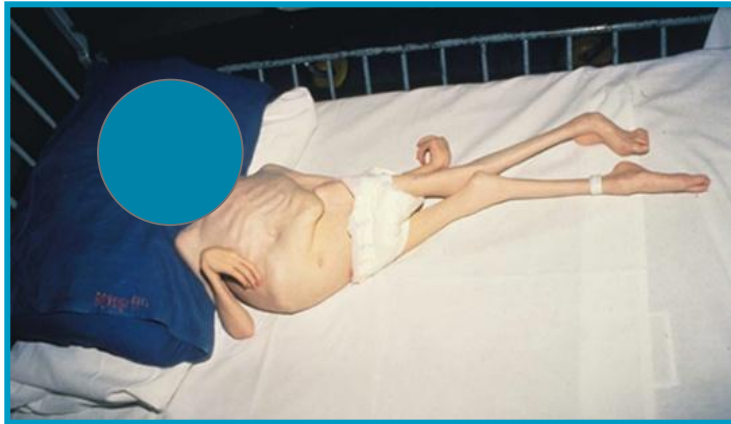




# GMFCS Level V

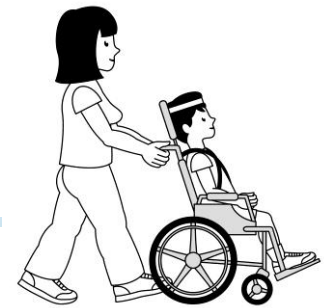


## Natural History vs Maximum Intervention

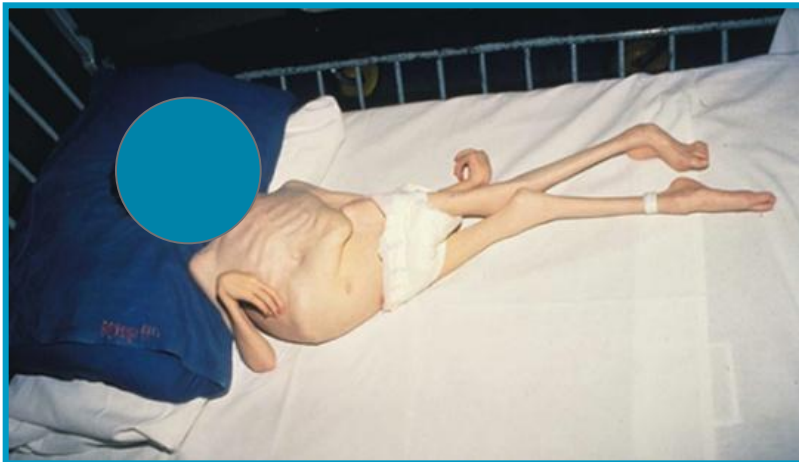




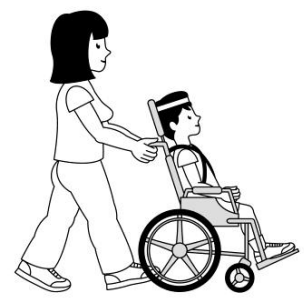
## GMFCS Level V



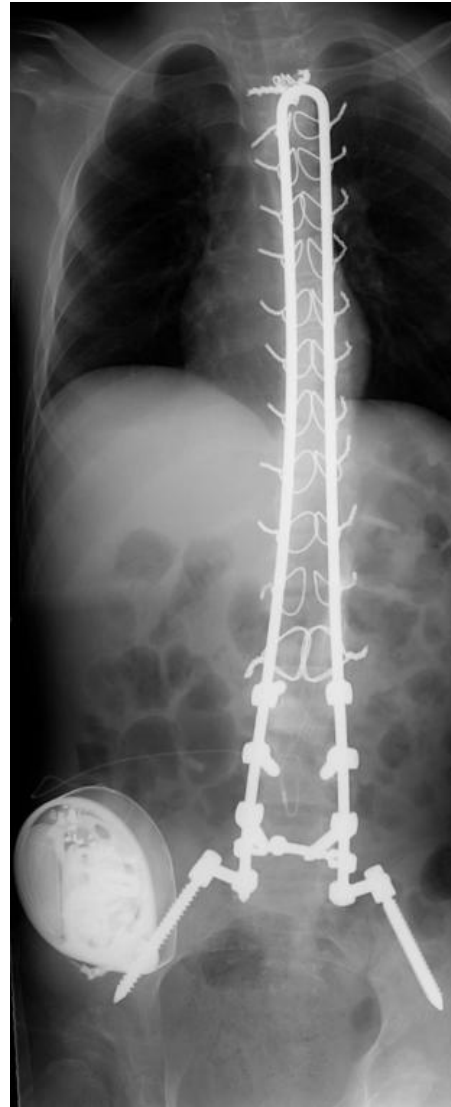
**Natural History vs Maximum Intervention**



**Economists: Can we afford to do this?**  
**Parents: Can we afford *not* to do this?**



# GMFCS Level V: Nutrition, respiratory function, tone, hips and spine.



# Questions in search of an answer...

---

- 1. Treat hip and spine GMFCS I-IV?**
- 2. What constitutes clinically and ethically appropriate orthopaedic care at GMFCS V?**
- 3. Specialized seating?**
- 4. Adductor surgery?**
- 5. Hip reconstruction?**
- 6. Scoliosis surgery?**
- 7. Does scoliosis surgery prolong life?**
- 8. Does scoliosis surgery improve QoL?**

# Cerebral Palsy in 2013.

---

- 1. CP remains the most common cause of physical disability, in developed countries.**
- 2. Management of GMFCS Levels I-IV seems cost effective and ethically fairly clear.**
- 3. GMFCS V is the most complex neurological disability, consistent with medium to long term survival.**
- 4. Posing enormous clinical, ethical, economic and social challenges to society, health care systems and government.**

# GMFCS V Cerebral Palsy in 2013.

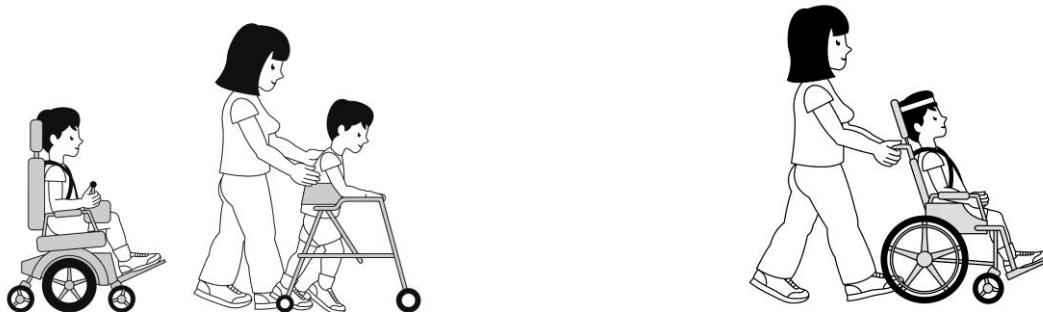
---

- 1. 40% mortality, at 22 years.**
- 2. What is clinically effective?**
- 3. What is cost effective?**
- 4. What improves QoL for the children?**
- 5. What improves QoL for parent, families and carers?**

# Quality of Life in Cerebral Palsy: Whose Life is it Anyway?

---

- 1. Disability rights.**
- 2. “Nothing about us, without us.”**
- 3. Valid approach for most CP.**
- 4. But serious difficulties, GMFCS V.**
- 5. Proxy reports from parents and carers.**



# Thank You

