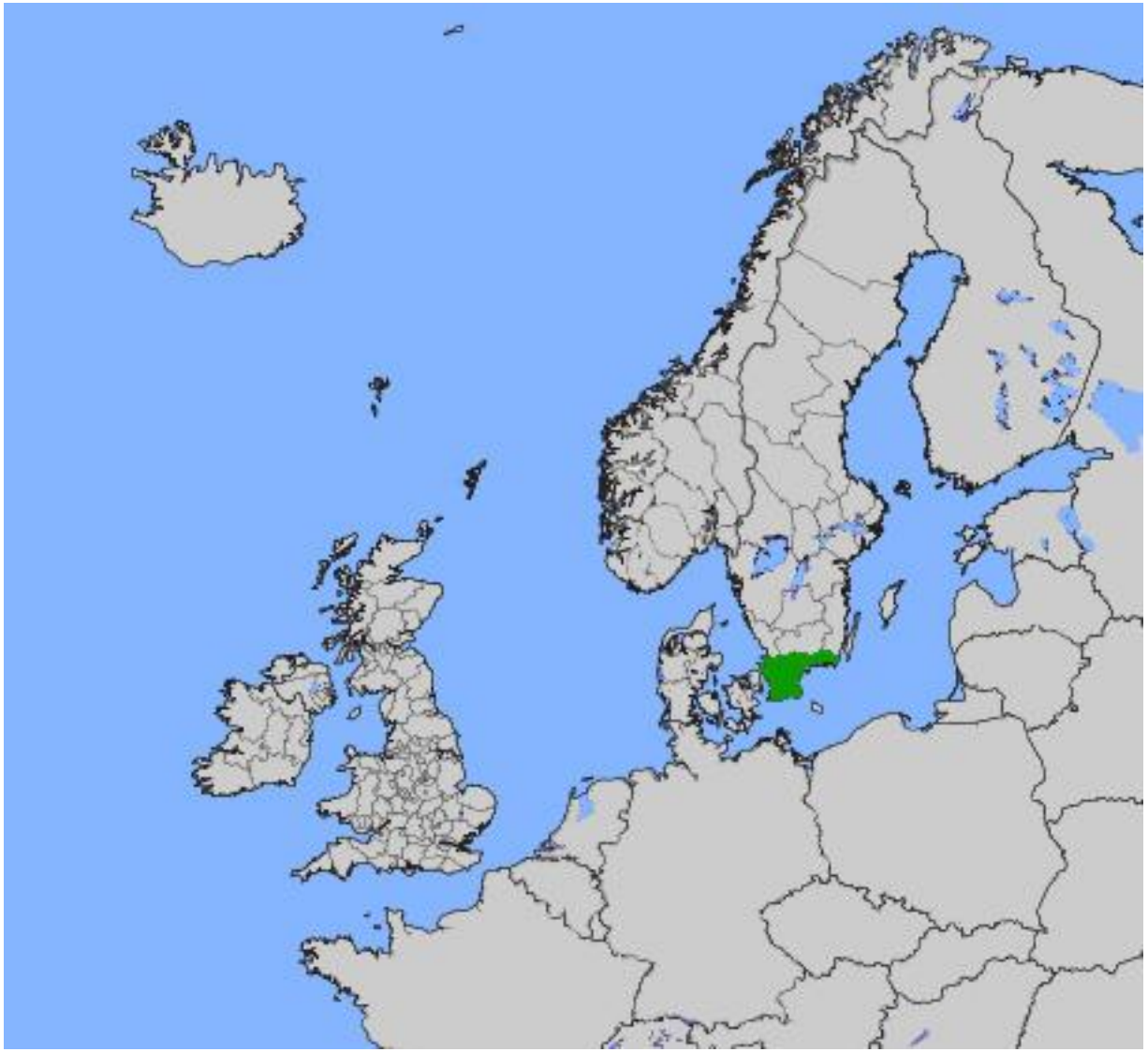
Cerebral Palsy Follow-up Program – CPOP

Reidun Jahnsen

PhD PT



1994

The Cerebral Palsy Follow-up Program, **CPUP**, a secondary prevention program and a national quality register, was established in Southern Sweden with children born from 1990

CPUP

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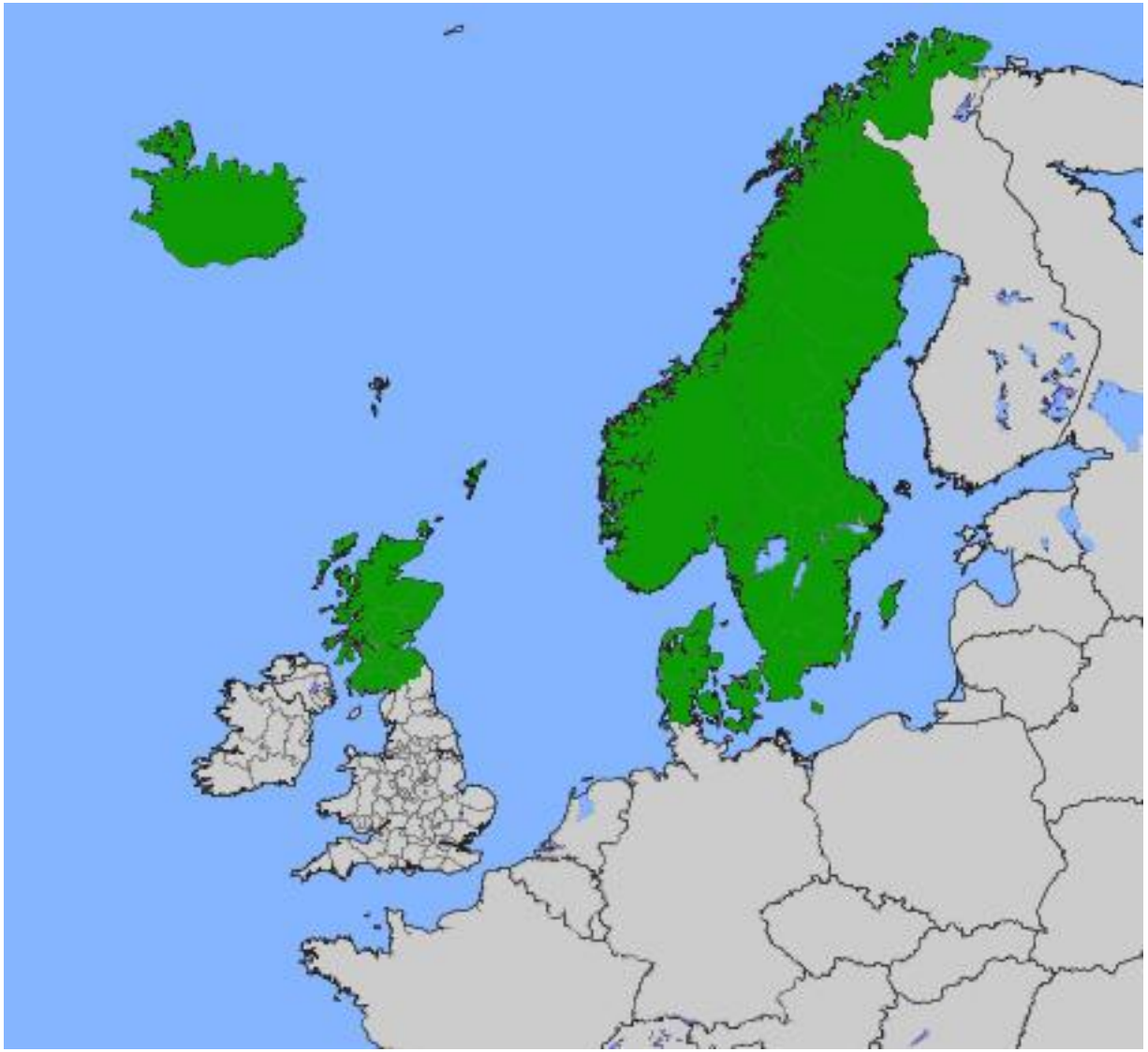
Why a secondary prevention program?

2014



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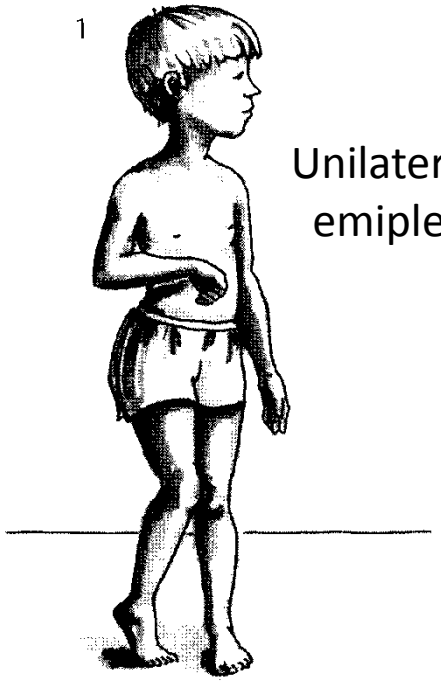
Cerebral palsy is an umbrella term

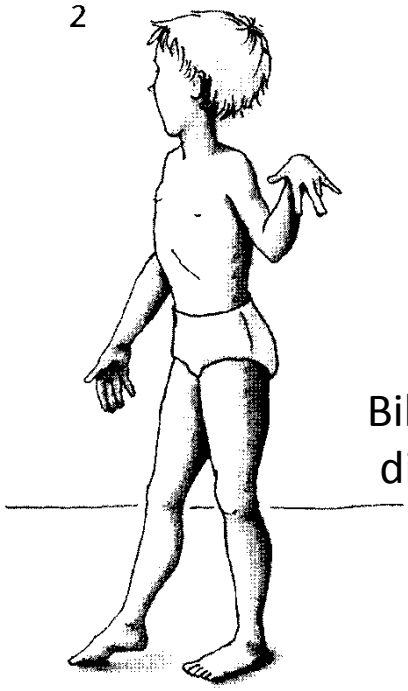
A group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain, often accompanied by disturbances of sensation, perception, cognition, communication, and behavior.
Rosenbaum et al 2007

Prevalence of CP is 2,3 per 1000 live births

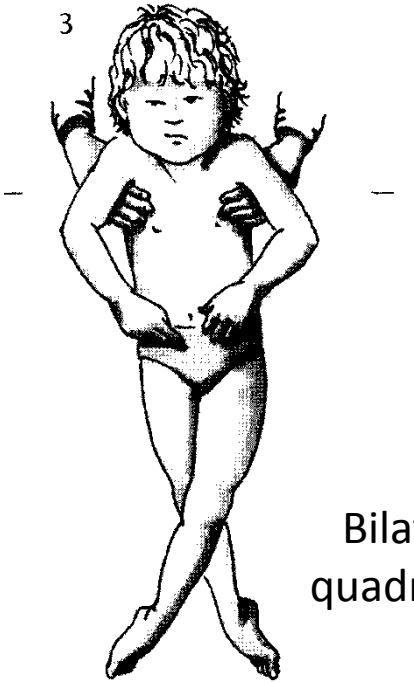
Andersen et al 2008



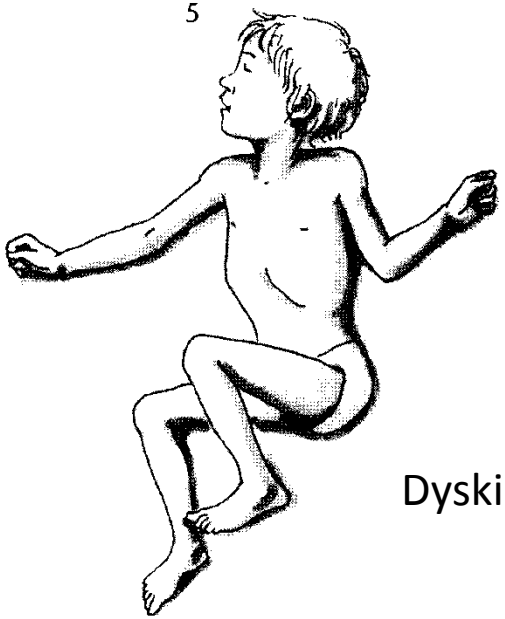
Unilateral/h emiplegia



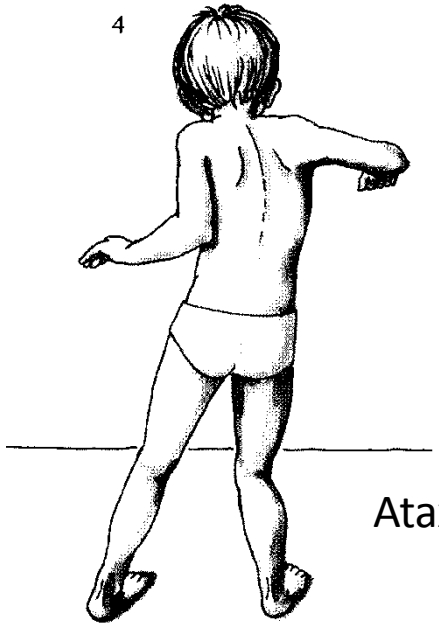
Bilateral/ diplegia



Bilateral/ quadriplegia



Dyskinetic



Ataxic

Subtypes of CP

Ill: Henje in Beckung et al2002

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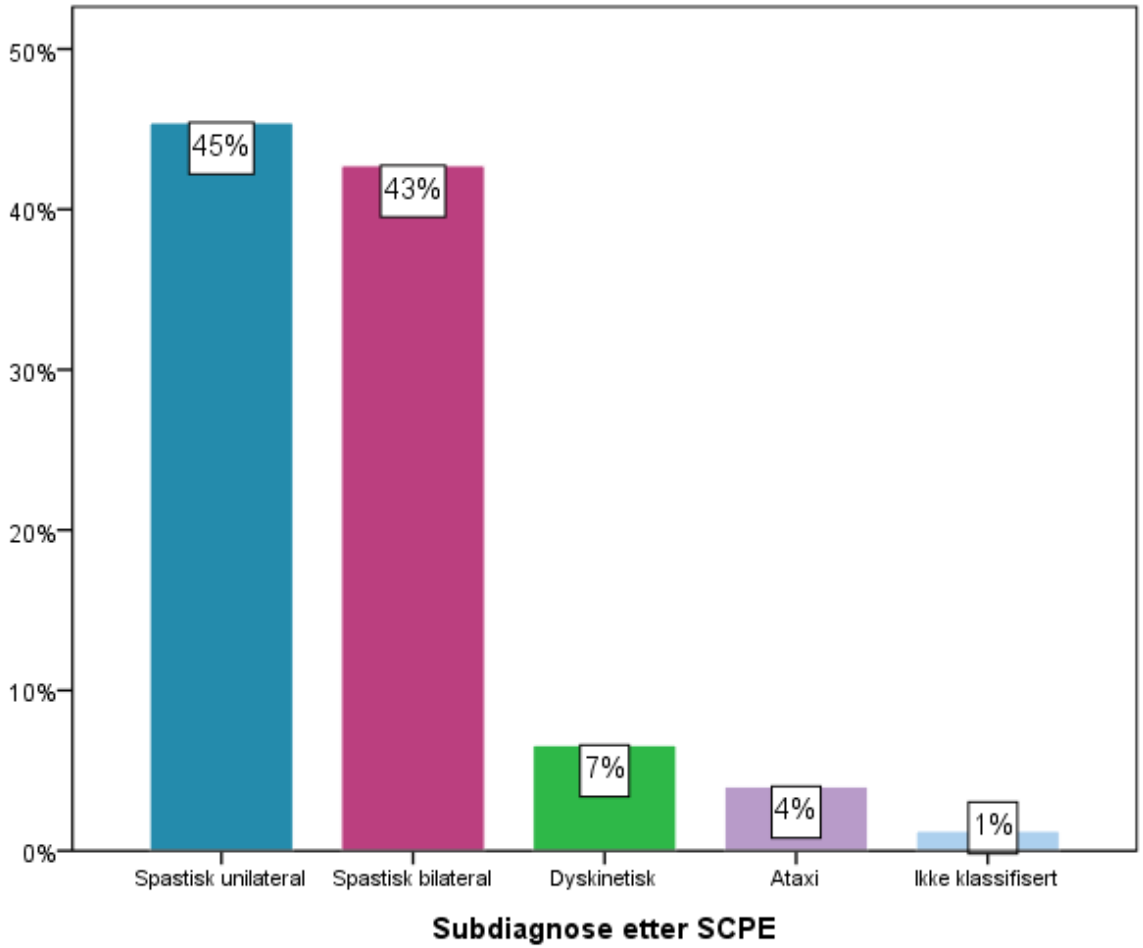
Subgroups of CP CPOP 2013 n= 972



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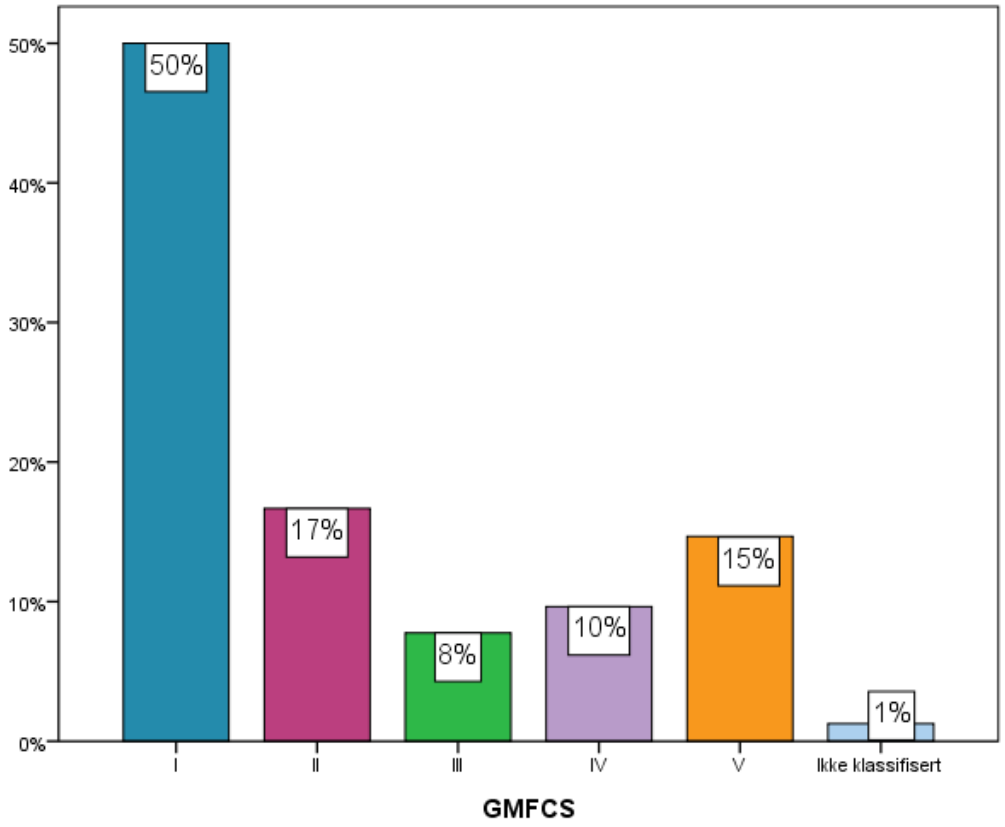
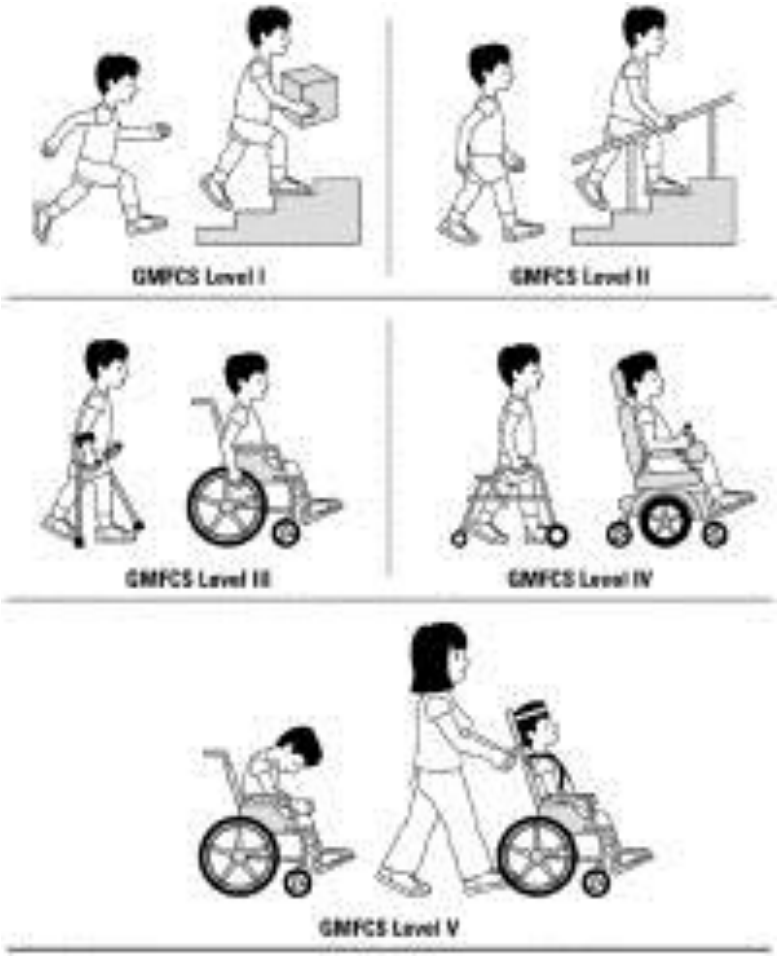
Gross Motor Function Classification System

Palisano 1997, CPOP 2013 n = 954





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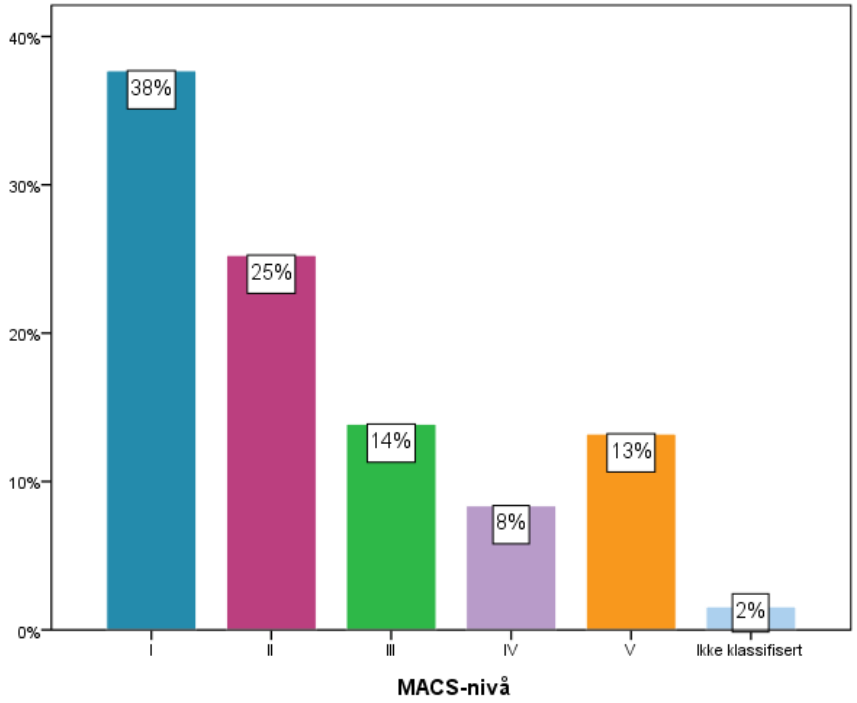
CPOP 2013 n=764

Manual Ability Classification System

- Classifies the ability to handle objects in daily life with two hands on a 5 point scale.
- Level one describes the best performance and level five the most severe impairment

Arner et al 2004



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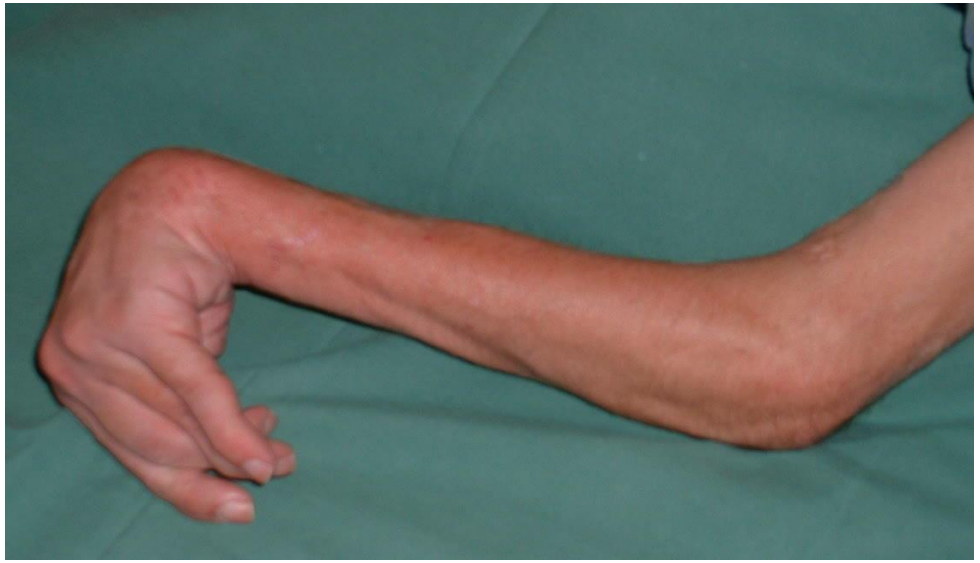
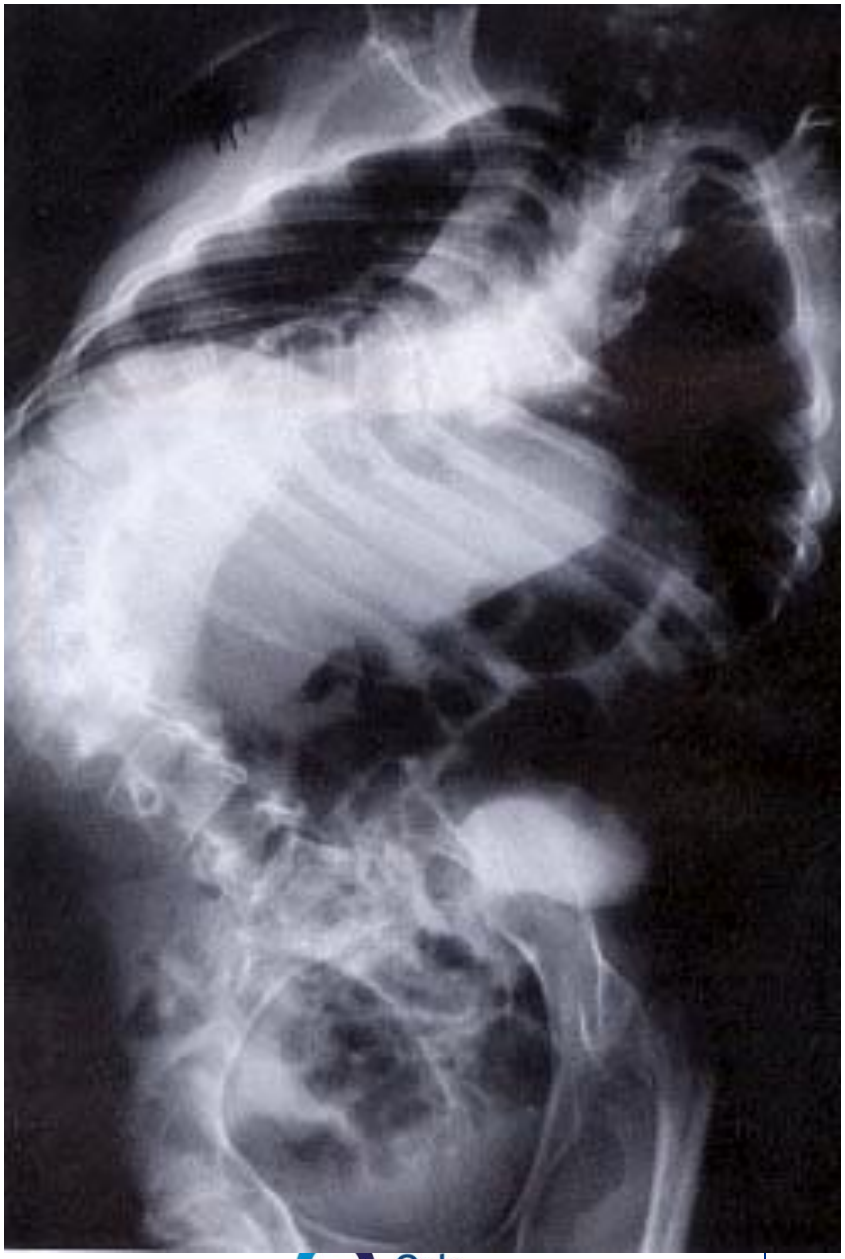
Why a secondary prevention program?

Development of contractures



Gravity rules



Aim

Prevent hipluxation and contractures and thereby contribute to optimising of function and quality of life

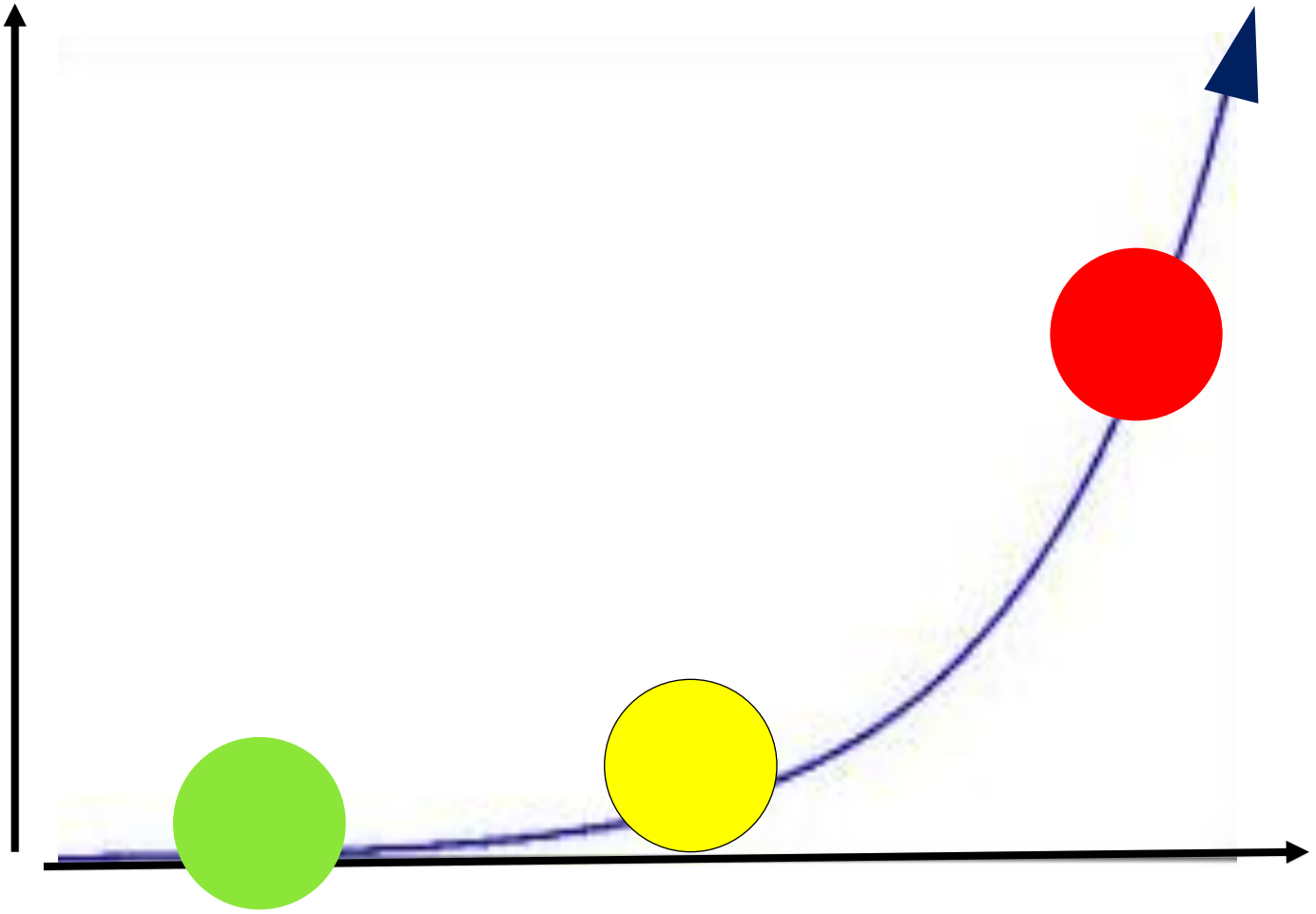
Improve collaboration

Increase knowledge of CP

Cut off values for range of motion and migration percentage of hips

- **GREEN Normal**
- **Yellow Control/intervention**
- **RED Pathologic/intervention**
- **Different cut off values depending on GMFCS level**
- **Clinical assessments according to a standardized protocol twice a year**
- **X-ray of the hips once a year**

Deformity



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After 10 years

- Hägglund G, Andersson S, Düppe H, Lauge-Pedersen H, Nordmark E, Westbom L. Pediatr Orthop. 2005;14:268-272. Prevention of severe contractures might replace multi-level surgery in CP. Results of a population based health care program and new techniques to reduce spasticity.

- Hägglund G, Andersson S, Düppe H, Lauge-Pedersen H, Nordmark E, Westbom L. Bone Joint Surg. 2005;87-B:95-101. Prevention of hip dislocation in children with cerebral palsy. The first ten years experience of a population-based prevention program.

- Arner M, Eliasson AC, Nicklasson S, Sommerstein K, Hägglund G. J Hand Surg. 2008;33A:1137-1347.Hand function in children with cerebral palsy. A population-based study of 367 children aged 4-14 years.

- Nordmark E, Hägglund G, Lauge-Pedersen H, Wagner P, Westbom L. BMC Medicine 2009, 7:65.Development of lower limb range of motion from early childhood to adolescence in cerebral palsy – a population based study.

- Roberts L. Lund University Hospital 2008, Cost benefit analysis of CPUP showed that being proactive is cheaper than being reactive

Before CPUP
Born 1990-91
N = 87

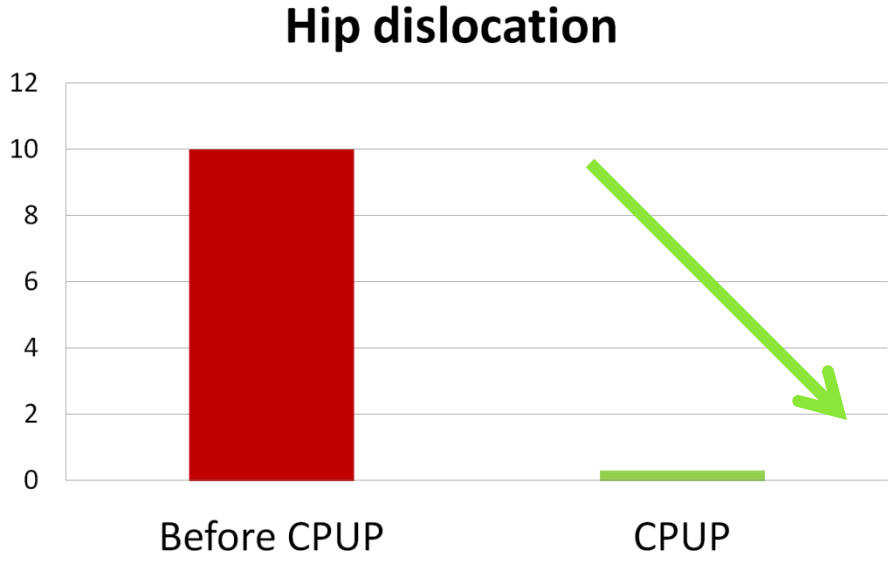
CPUP
Born 1992-2007
N = 689

Hip dislocation

N = 9 (10%)

Hip dislocation

N = 2 (0.3%)



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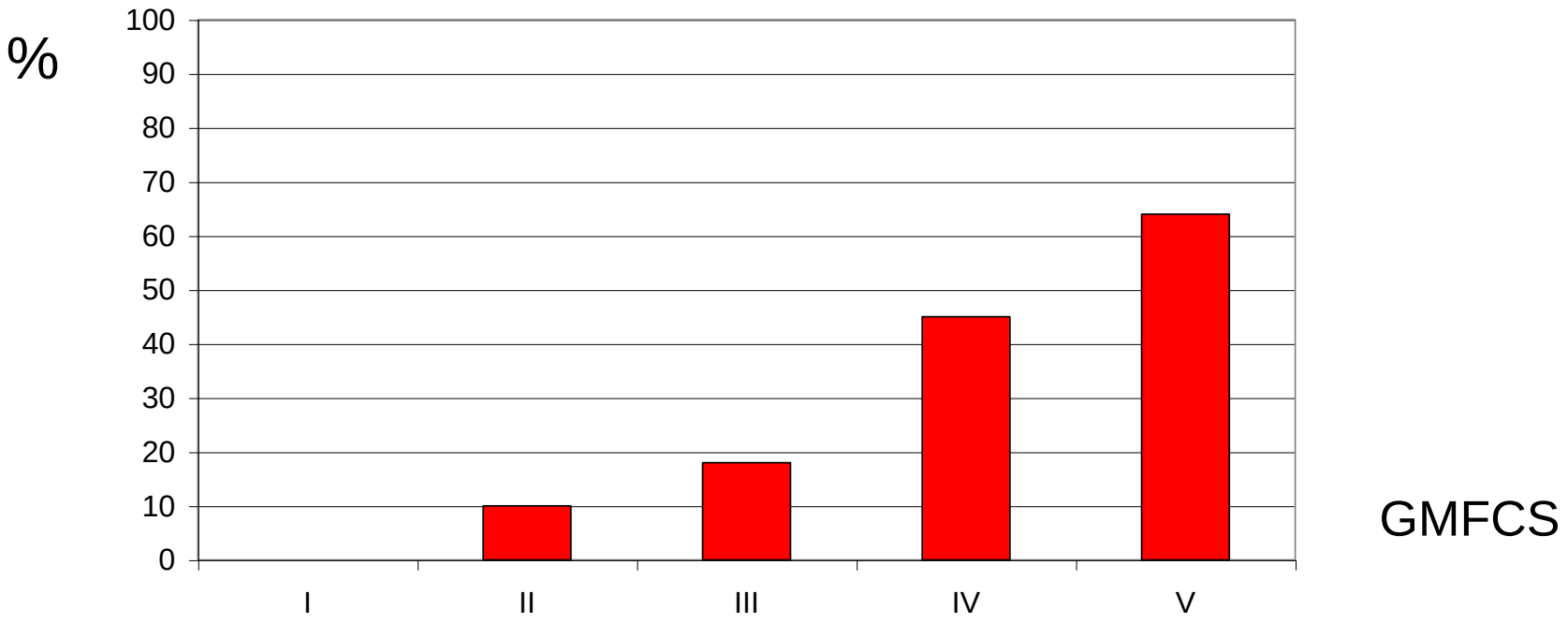
- The Cerebral Palsy Follow-up Program (CPOP) was implemented in South-Eastern Norway in 2006 and nationally in 2010
- Close collaboration with the CP-register in Norway (CPRN)
- Nearly all children with CP born from 2002 in South-Eastern Norway and from 2006 in the rest of the country are registered
- Multidisciplinary teams in 21 habilitation units assess their motor function according to the standardised protocol
- The assessments are performed once or twice a year or every second year depending on age and functional level

Hip displacement related to GMFCS



Characteristics of children with hip displacement in cerebral palsy

Gunnar Hägglund*[1], Henrik Lauge-Pedersen[1] and Philippe Wagner[2]

BMC Musculoskeletal Disorders 2007, ***8:101***

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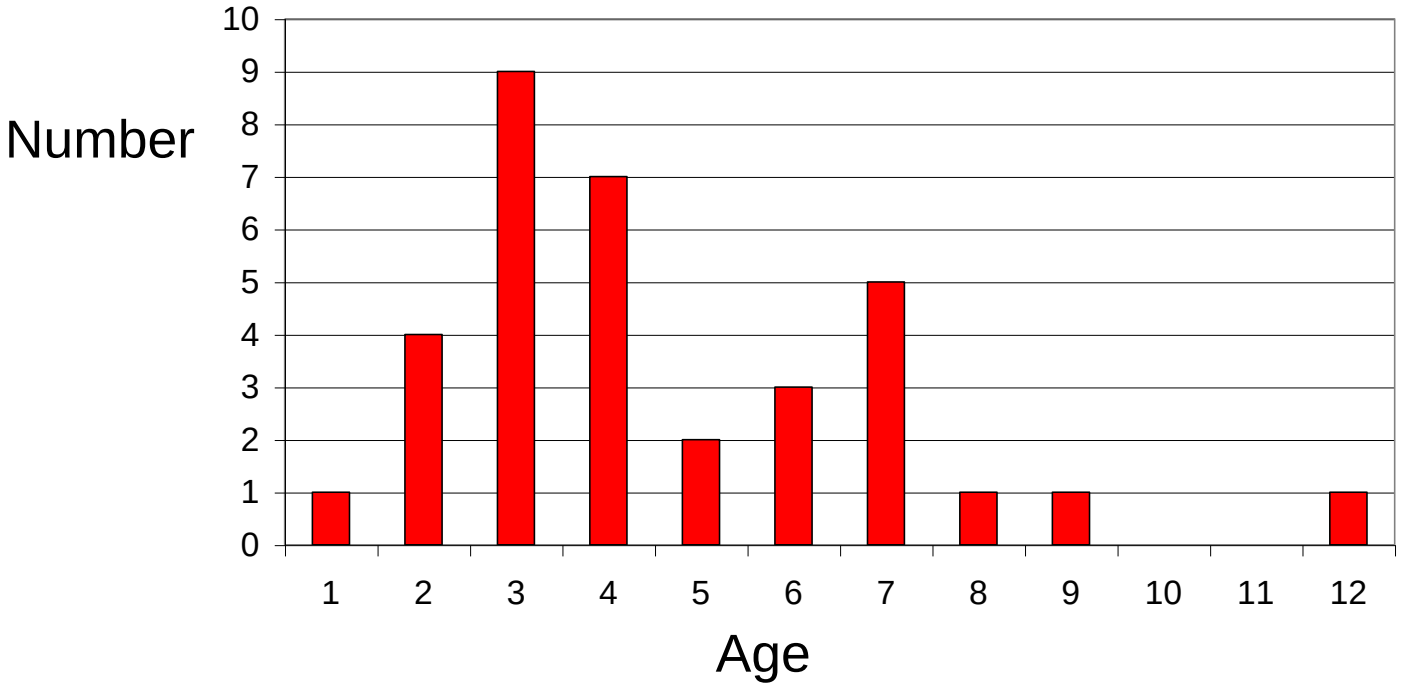
Hip displacement related to age



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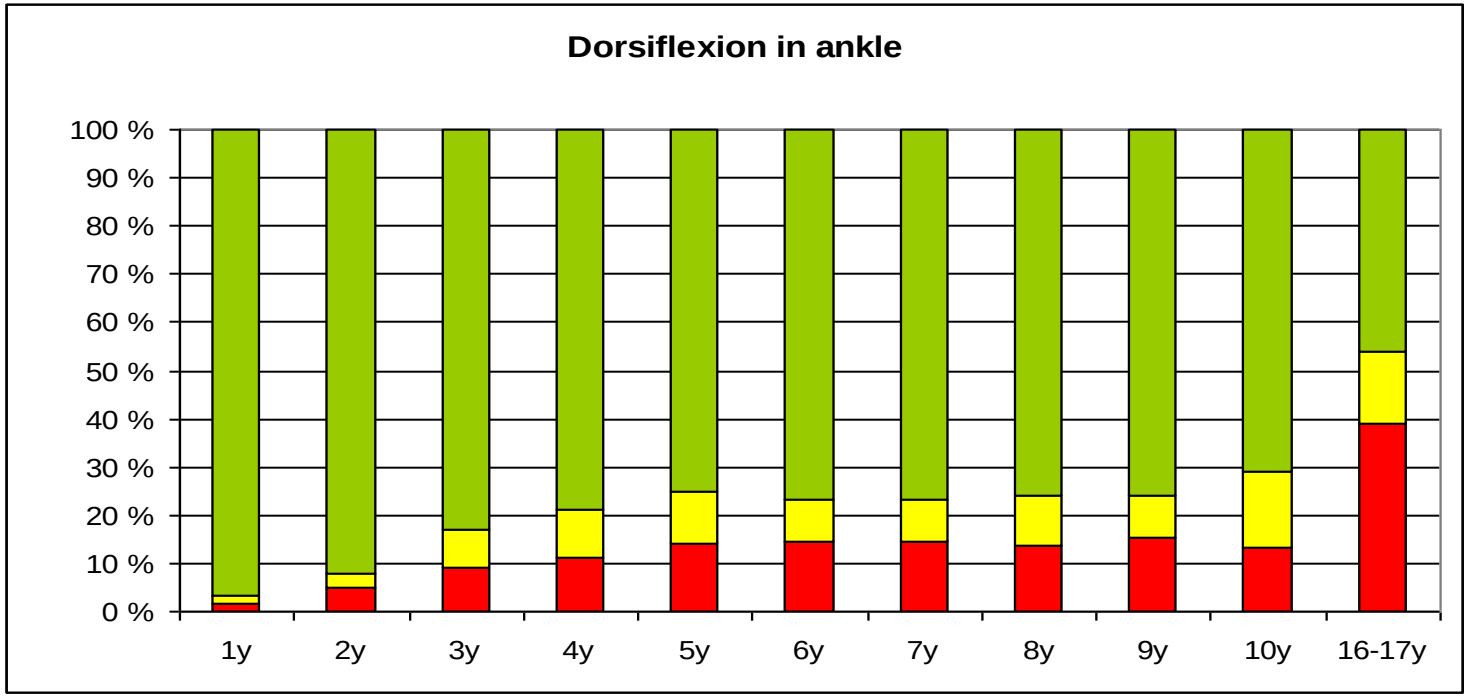
Dorsiflexion in ankle

Jahnsen, Myklebust, Elkjær, Ramstad 2009

830 children with CP (CPOP 2012) and 76 youth with CP



Green = normal

Yellow = control/intervention

Red = pathologic

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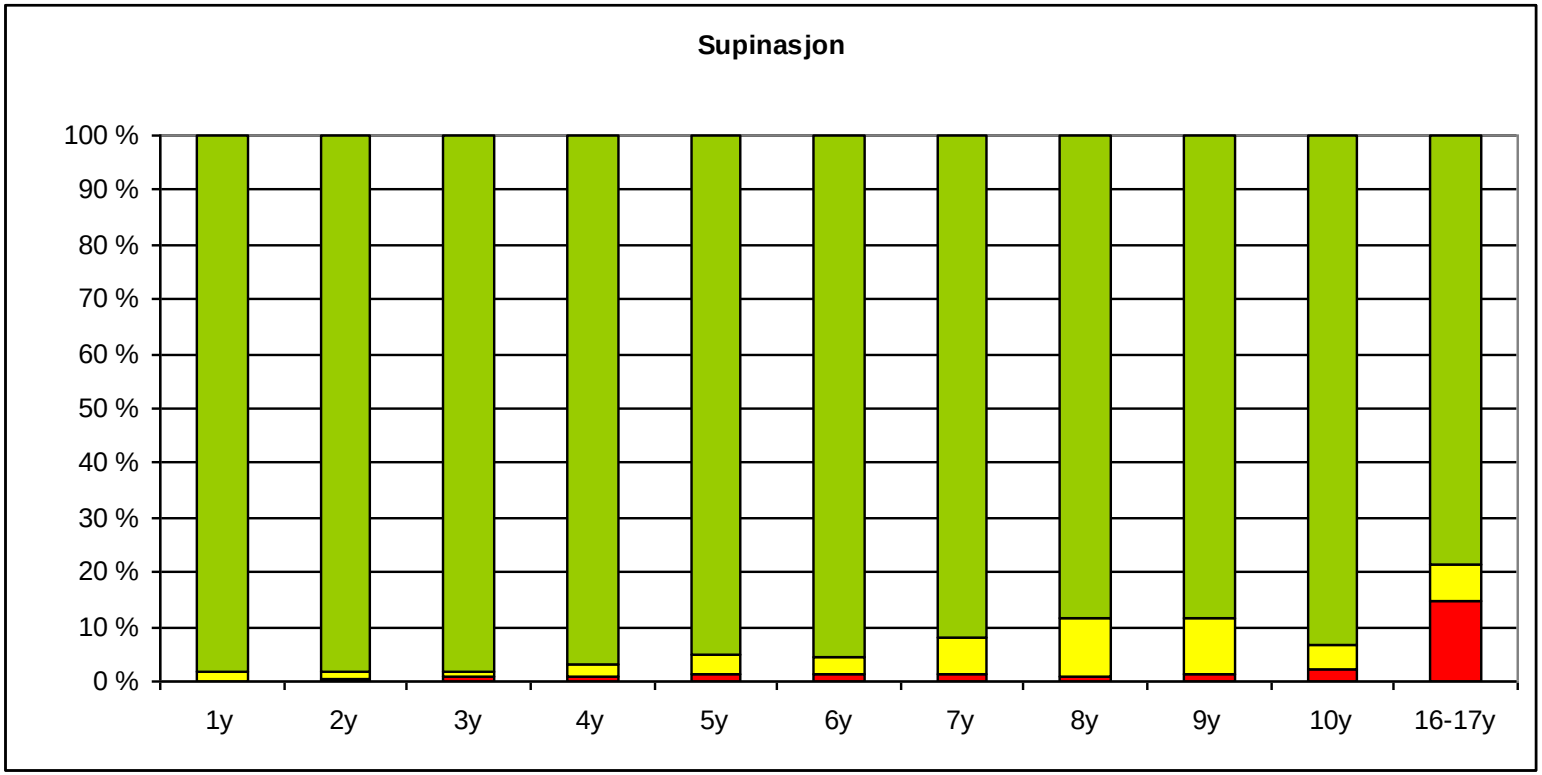
Supination of forearm

Elkjær, Myklebust, Jahnsen 2009



598 children with CP (CPOP 2012) and 76 youth with CP

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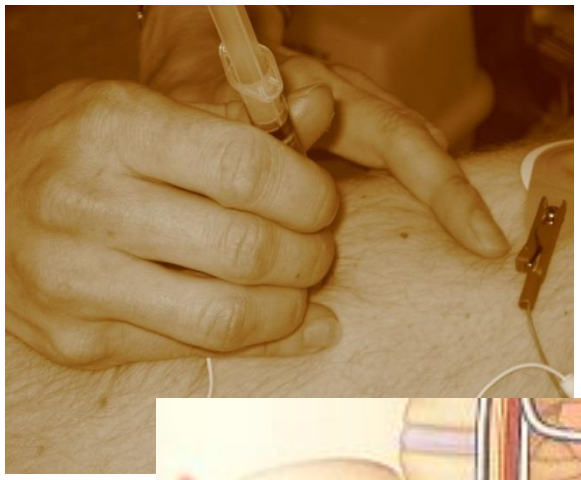
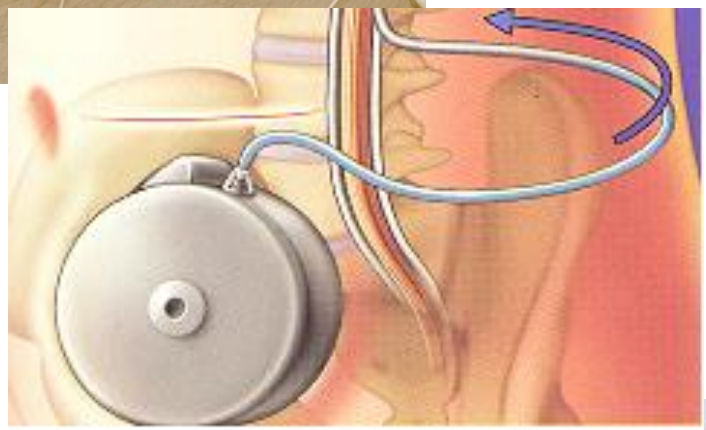
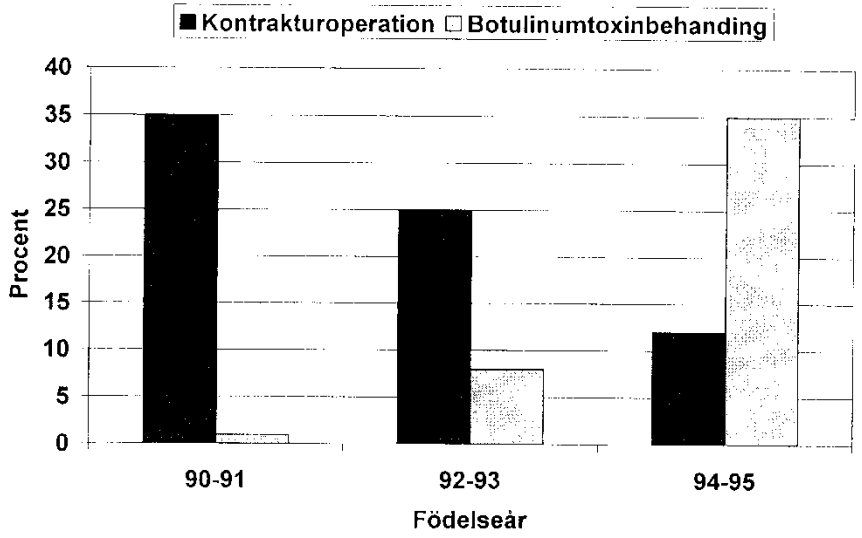
Registration of interventions

- Botulinum toxin-A
- Intrathecal Baklofen
- Orthoses
- Intensive goal-directed training
- 24 hours positioning
- Preventive surgery





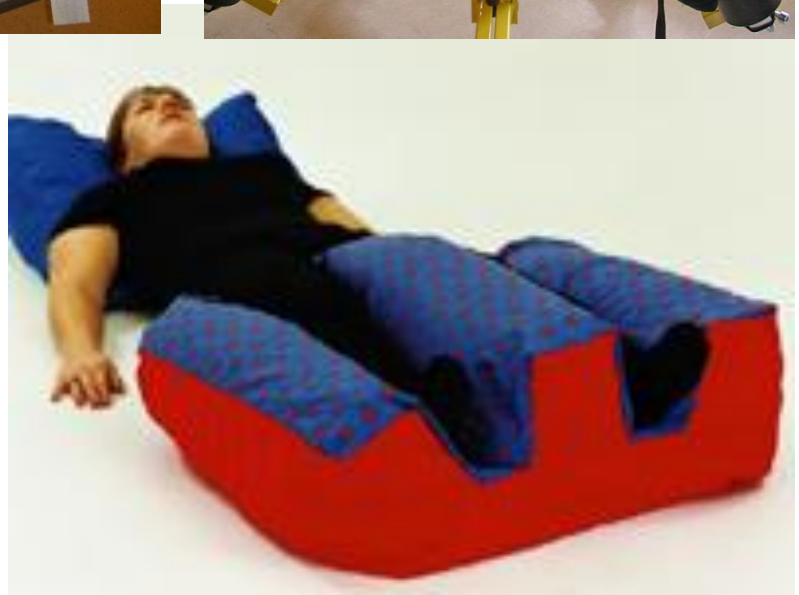


CPOP – a gold mine for research

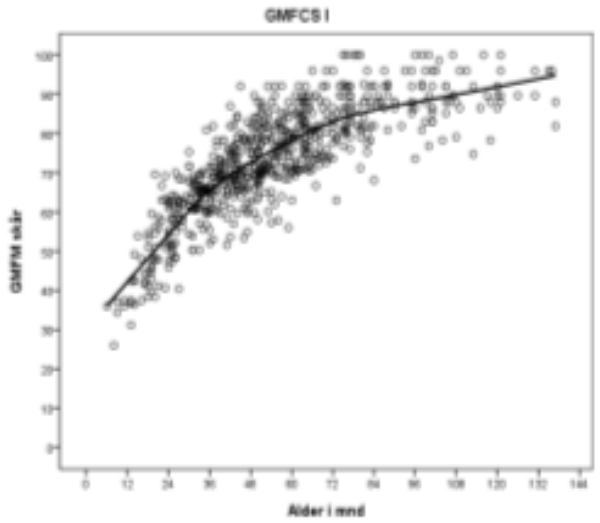
- Population based data
- Large samples
- Standardized follow-up
- Life span follow-up

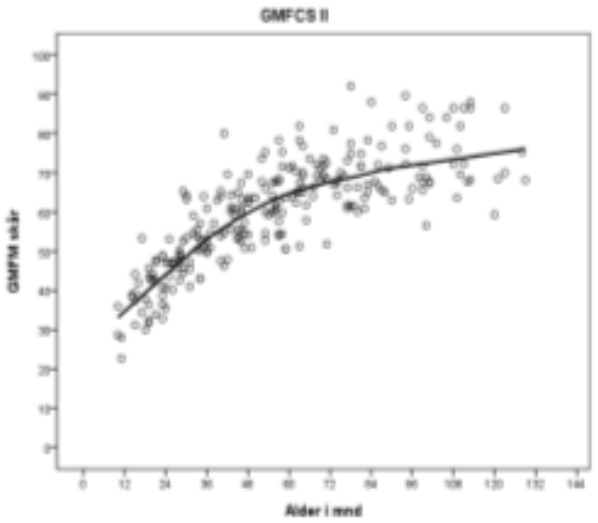
- Three PhDs accomplished and eight ongoing
- 35 articles published www.cpup.se
- EU application with five countries
  - Health, Quality of life and participation
  - Family
  - Cost-effectiveness and economic modeling
  - Program satisfaction of CPUP
  - Implementation and feasibility

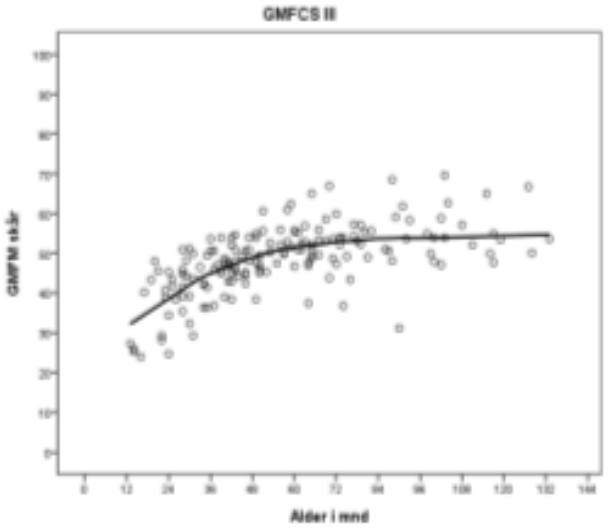
Martinsson C, Himmelmann K. Effect of weight-bearing in abduction and extension on hip stability in children with cerebral palsy. Pediatr Phys Ther 2011;23:150-7.

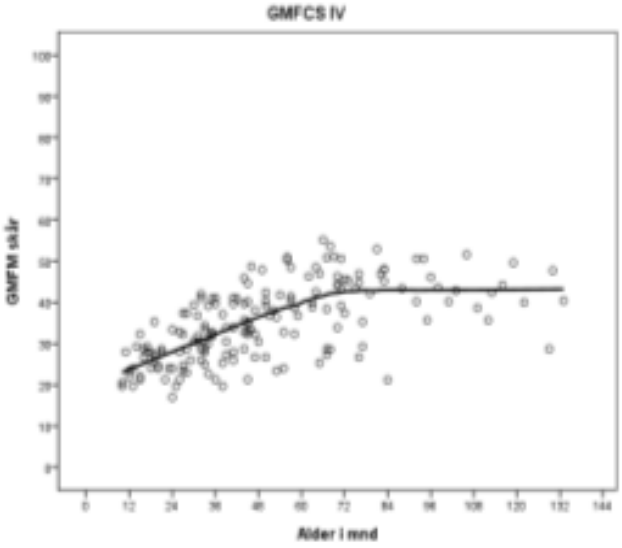


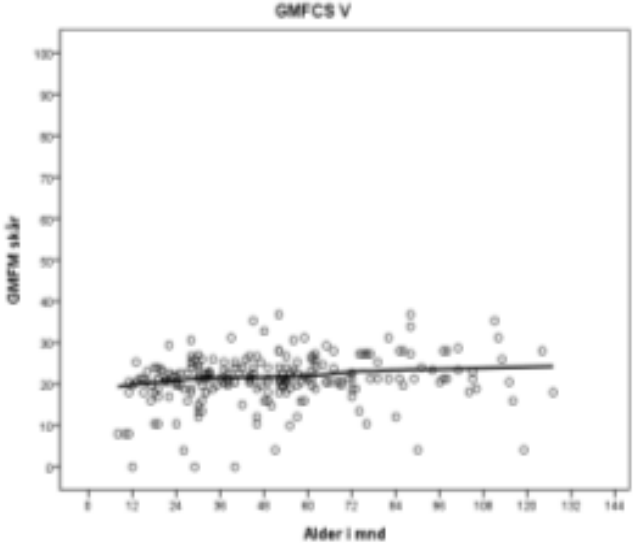
Development of gross motor function











n=1488 GMFM-tests of 593 children
Myklebust et al 2014

Windswept hip deformity in children with cerebral palsy

Måns Persson-Bunke, Gunnar Hägglund and Henrik Lauge-Pedersen

Journal of Pediatric Orthop B 2006;15:335-338

The proportion of children with windswept deformity is significantly reduced with CPOP

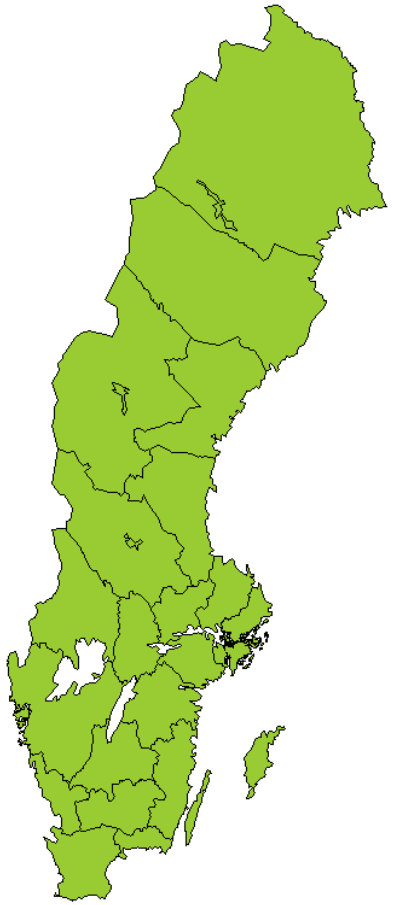
Prevention of hip dislocation in CPUP

- Without treatment 15% of all children with CP would have hip dislocation
- Without treatment 40% of all children at GMFCS IV-V would have hip dislocation
- Of 3125 children 0-18 years there are 13 with hip dislocation = 0.4%

Prevention of hip dislocation in children with cerebral palsy. Twenty years result of a population-based prevention program

The Bone and Joint Journal. 2014; 96-B:1546-52

Hägglund G, Alriksson Schmidt A, Lauge Pedersen H, Rodby-Bousquet E, Westbom L



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Evaluation of CPOP in Norway

- I got adequate information about CPOP in advance
- CPOP leads to many unnecessary assessments of the child
- CPOP contributes to optimal timing of the interventions for the child
- CPOP leads to increased knowledge about CP
- CPOP makes the follow-up more predictable
- CPOP leads to little time for issues that are not related to CPOP
- CPOP contributes to more equal treatment in the whole country
- CPOP contributes to better partnership with the families
- I would have declined joining CPOP if I was asked today **(P)**
- I felt pressured to join the CPOP **(P)**
- CPOP contributes to improved quality of the services **(H)**
- CPOP uses resources at the expense of other diagnostic groups **(H)**

- **A 4-point Likert scale was used**

Jahnsen, Ramstad, Elkjær, Myklebust 2010

Results

- 223 of 297 parents (75%) responded
- 61% mothers, 10% fathers, 26% both parents, and 4% other caregivers
- 137 health professionals responded, 68% physiotherapists, 23% occupational therapists, 7% paediatricians and 2% leaders, 64% worked in primary health care and 36% in ten habilitation units
- The most frequently reported challenge was coordination of the services, both across professional as well as administrative borders

Conclusion

- Both parents and health professionals thought that CPOP makes the follow-up of children with CP more predictable, more equally distributed, giving more optimal timing of interventions
- The assessments should be used as sessions of dialogue and exchange of knowledge
- Differentiation of assessment frequency for different subtypes of CP has been implemented along with increased knowledge
- The success of CPOP calls for systematic follow-up programs in other areas, such as nutrition, communication and cognition, and for other diagnostic groups with life span disabilities

Future challenges