



NORWEGIAN CEREBRAL PALSY REGISTRY

National medical quality registry

Registration at age 5

To be filled out by CPRN

1. Form number

2. Parental consent Yes (only if consent is not enclosed from the first time registration)

3. Birthdate & identification number (11 digits)

4. Date of present clinical examination: (8 digits)

5. Born in Norway Yes No Unknown

7. County of residence

6. Growth Height

8. Status Living Deceased

Weight

9. If deceased, date of death

10. Age at death months

11. Sex Male Female

12. Presumed postneonatal cause? Yes No Unknown

13. ICD-10 code postneonatal cause of CP?

14. Text diagnosis of postneonatal cause?

15. Age at time of the insult? months

16. Diagnosis

SCPE

ICD 10

Spastic Unilateral Hemiplegia, right G 80.2

Hemiplegia, left G 80.2

Bilateral Diplegia G 80.1

Quadriplegia G 80.0

Dyskinetic Choreoathetosis G 80.3

Dystonia G 80.3

Ataxia G 80.4

Age at diagnosis, in months months

Not CP

See description of Levels on page 7 and 8

17. Gross Motor Function Classification Scale I II III IV V Unknown

18. Bimanual Fine Motor Function Scale I II III IV V Unknown

19. Manual Ability Classification System I II III IV V Unknown

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20. Have cognitive abilities been assessed?

- 11 Test with IQ scores
- 12 Test without IQ scores
- 20 Unable to test
- 0 Unknown

21. Which assessment methods/tests have been utilised?

22. Result

- 10 IQ <50 (Moderate to profound intellectual disability)
- 21 IQ 50-69 (Mild intellectual disability)
- 22 IQ 70-84
- 23 IQ >= 85
- 0 Unknown
- 24 Nonverbal learning disorders
- 25 Verbal learning disorders

23. Age at assessment months

24. Child has been clinically assessed only

- 11 Considered to have normal intellectual ability
- 12 Considered intellectually disabled
- 0 Unknown

25. Is the child visually impaired?

- 1 Yes 2 No 0 Unknown

26. Does the child have a serious visual impairment?
(blind i.e. <6/60 (<0.1) with correction, in best eye)

- 1 Yes 2 No 0 Unknown

27. Is the child hearing impaired?

- 1 Yes 2 No 0 Unknown

28. Does the child have a serious hearing impairment?
(hearing loss >70dB before correction, in best ear)

- 1 Yes 2 No 0 Unknown

29. Does the child have/has the child had epilepsy?
(at least 2 unprovoked seizures during the postneonatal period)

- 1 Yes 2 No 0 Unknown

30. Does the child use antiepileptic drugs now?

- 1 Yes 2 No 0 Unknown

31. Has language understanding been assessed? 32. Which assessment methods were utilised?

- 1 Yes, formally assessed?
- 11 Yes, clinically assessed?
- 2 No
- 0 Unknown

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33. Language understanding (compared with healthy peers)

10	<input type="checkbox"/> Normal	12	<input type="checkbox"/> Moderately impaired
11	<input type="checkbox"/> Slightly impaired	13	<input type="checkbox"/> Does not understand speech
0	<input type="checkbox"/> Unknown		

34. Speech function

1	<input type="checkbox"/> Normal	2	<input type="checkbox"/> Difficult to understand
3	<input type="checkbox"/> Slightly difficult to understand	4	<input type="checkbox"/> Very difficult to understand
5	<input type="checkbox"/> Ingen tale	0	<input type="checkbox"/> Unknown

35. Does the child communicate by use of graphic communication aids?

10	<input type="checkbox"/> Printer	11	<input type="checkbox"/> Bliss	12	<input type="checkbox"/> Pictogram
13	<input type="checkbox"/> Pictures	2	<input type="checkbox"/> Does not use		
0	<input type="checkbox"/> Unknown				

36. Does the child communicate by use of hand signals, signs or gestures?

1	<input type="checkbox"/> Yes	2	<input type="checkbox"/> No	0	<input type="checkbox"/> Unknown
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37. Does the child have eating difficulties?

1	<input type="checkbox"/> Yes	2	<input type="checkbox"/> No	0	<input type="checkbox"/> Unknown
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38. How is the child fed?

10	<input type="checkbox"/> Eats without assistance	21	<input type="checkbox"/> Eats with assistance
22	<input type="checkbox"/> Must be fed (orally)	30	<input type="checkbox"/> Partially tube fed
31	<input type="checkbox"/> Mainly tube fed	0	<input type="checkbox"/> Unknown

39. Gastrostomy

1	<input type="checkbox"/> Yes	2	<input type="checkbox"/> No	<input type="text"/> months
0	<input type="checkbox"/> Unknown			

40. Age at gastrostomy?

1	<input type="checkbox"/> Yes	2	<input type="checkbox"/> No	0	<input type="checkbox"/> Unknown
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41. Has the child received drug treatments for spasticity?

42. Has the child received Botulinum toxin?

1	<input type="checkbox"/> Yes	11	<input type="checkbox"/> i underex	21	<input type="checkbox"/> i overex
2	<input type="checkbox"/> No	0	<input type="checkbox"/> Unknown		

43. Has the child received oral Baclofen?

1	<input type="checkbox"/> Yes	2	<input type="checkbox"/> No	0	<input type="checkbox"/> Unknown
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44. Does the child have an Intrathecal Baclofen pump?

1	<input type="checkbox"/> Yes	2	<input type="checkbox"/> No	0	<input type="checkbox"/> Unknown
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45. When did the child receive a Baclofen pump? (months)

<input type="text"/> months

46. Has the child had orthopaedic surgery?

1	<input type="checkbox"/> Yes	11	<input type="checkbox"/> in lower extremities	21	<input type="checkbox"/> in upper extremities	31	<input type="checkbox"/> Soft tissue surgery	41	<input type="checkbox"/> Bone surgery
2	<input type="checkbox"/> No	0	<input type="checkbox"/> Unknown						

47. Hand function – right hand

1	<input type="checkbox"/> Normal function	2	<input type="checkbox"/> A few visible motor signs, but near normal function
3	<input type="checkbox"/> Clearly reduced function	0	<input type="checkbox"/> Unknown
4	<input type="checkbox"/> Seriously reduced function (little functional movement)		

48. Hand function – left hand

- 1 Normal function
- 2 A few visible motor signs, but near normal function
- 3 Clearly reduced function
- 4 Seriously reduced function (little functional movement)
- 0 Unknown

49. Walking ability

- 1 Normal function
- 2 Clear motor signs, but walks without assistance
- 3 Walks with assistive mobility devices
- 4 Unable to walk, even with assistive devices; wheelchair-dependent
- 0 Unknown

50. Sitting ability

- 1 Normal, stable sitting ability
- 2 Mildly reduced function, somewhat unstable sitting ability
- 3 Sits only with support
- 4 Unable to sit, even with support
- 0 Unknown

51. Does the child have associated syndromes?

1 Yes 2 No 0 Unknown

52. What is the ICD-10 code of the syndrome?

53. What is the text diagnosis of the syndrome?

54. Does the child have congenital anomalies?

1 Yes 2 No 0 Unknown

55. What is the ICD-10 code of the anomaly / anomalies?

56. What is the text diagnosis of the anomaly / anomalies?

57. Does the child have a brain malformation?

1 Yes 2 No 0 Unknown

58. What is the ICD-10 code of the brain malformation?

59. What is the text diagnosis of the brain malformation?

60. Comments

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QUESTIONS 61-65 CONCERN CEREBRAL MRI

61. Has a cerebral MRI been performed?

1 Yes 2 No 0 Unknown62. Age at MRI? months

63. Main morphological findings (pathology)

White matter injury of immaturity (PVL, PVH etc)	11 <input type="checkbox"/>	Yes	Focal cortical lesion	21 <input type="checkbox"/>	Yes	Diffuse cortical lesion	31 <input type="checkbox"/>	Yes
Basal ganglia pathology	41 <input type="checkbox"/>		Malformation	51 <input type="checkbox"/>		Normal findings	61 <input type="checkbox"/>	

64. Lesion localisation

(N.B.! Mark only (1) box!)

Bilateral lesions	11 <input type="checkbox"/>	Yes
Lesion localised on right side, or largest on right side	21 <input type="checkbox"/>	
Lesion localised on left side, or largest on left side	31 <input type="checkbox"/>	

65. Other findings

(More than one mark permitted)

Cerebellum	3 <input type="checkbox"/>	Normal	4 <input type="checkbox"/>	Pathological
Corpus callosum	5 <input type="checkbox"/>	Normal	6 <input type="checkbox"/>	Pathological
Signs of infection (Ca++)	101 <input type="checkbox"/>	Yes	102 <input type="checkbox"/>	No

FORM FILLED OUT BY:

Name: Position: Institution: Date: Place: 

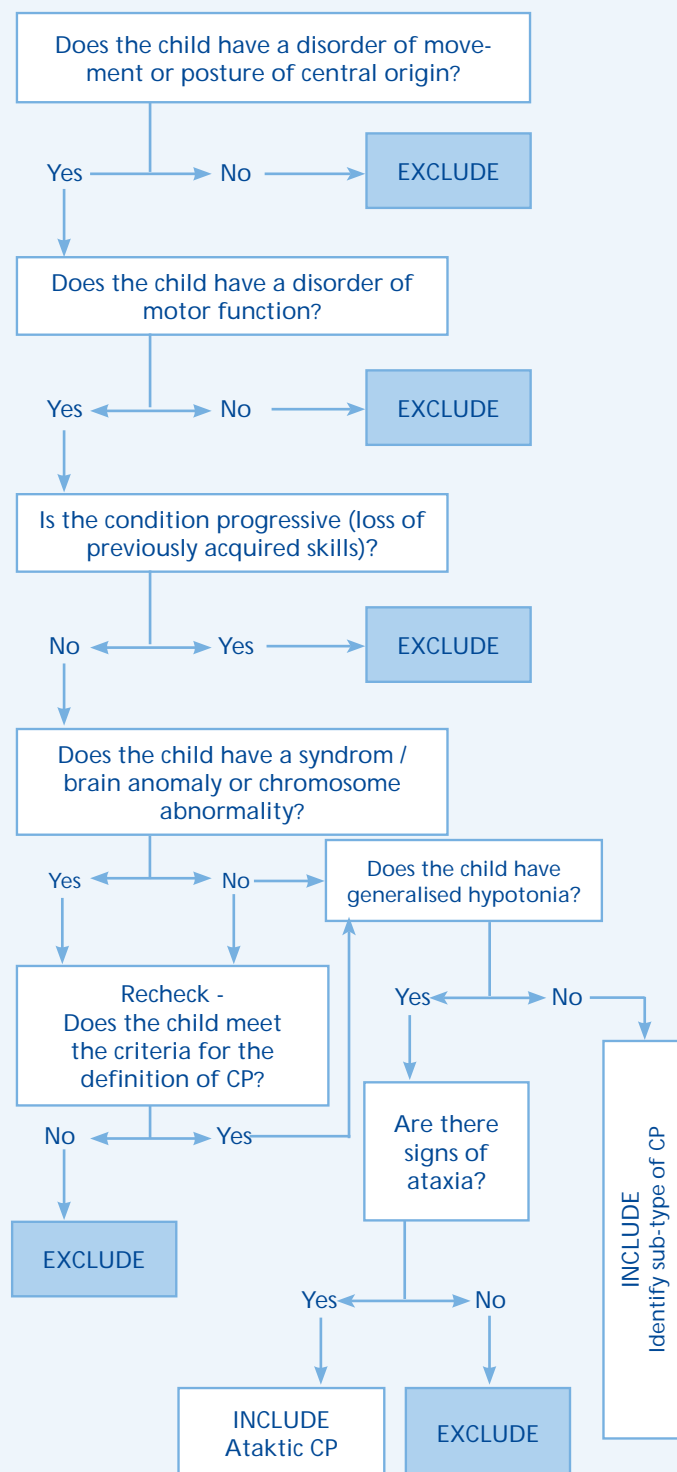
Sykehuset i Vestfold

HELSE SØR-ØST

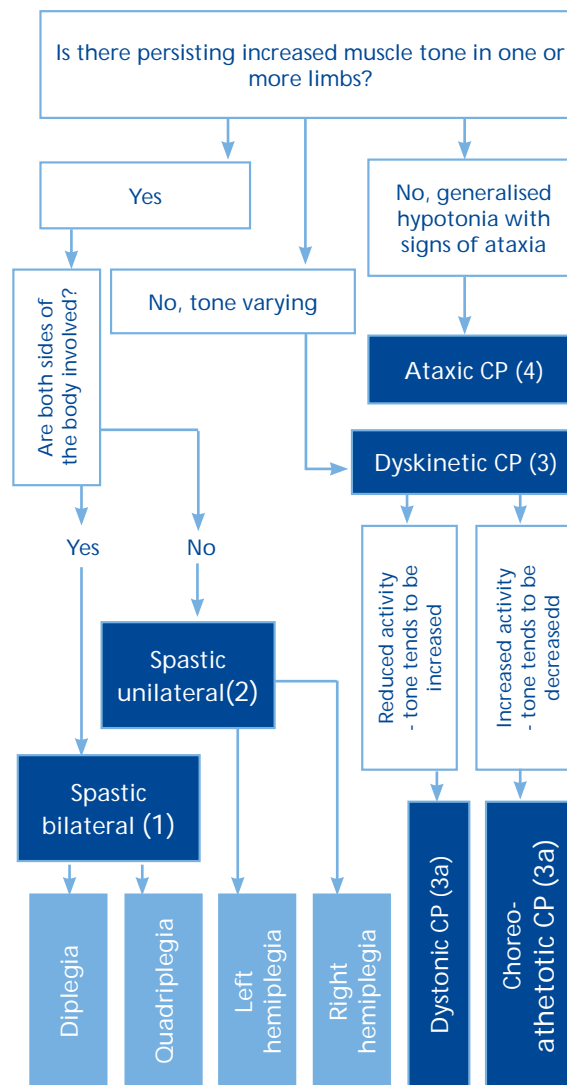
In cooperation with:

Medical Birth Registry, The Norwegian Institute of Public Health,
The Norwegian University of Science and Technology (NTNU), The Cerebral Palsy
Follow-up Program (CPOP) Project, Norwegian Cerebral Palsy Association.

DECISION TREE for identifying cerebral palsy



CLASSIFICATION TREE for sub-types of cerebral palsy



Definitions of cerebral palsy types

Spastic Cerebral Palsy is characterised by at least two of:

- Abnormal pattern of posture and/or movement
- Increased tone (not necessarily constantly)
- Pathological reflexes (hyper-reflexia or pyramidal signs e.g. Babinski response)

Both sides of the body involved = **1. Spastisk bilateral CP**
 One side of body involved = **2. Spastisk unilateral CP**

3. Dyskinetic Cerebral Palsy is characterised by both of:

- Involuntary, uncontrolled, recurring, occasionally stereotyped movements of affected body parts
- Involuntary, uncontrolled, recurring, occasionally stereotyped movements of affected body parts
 - 3a. Dystonic Cerebral Palsy, dominated by both:
 - o Hypokinesia
 - o Hypertonia
 - 3b. Choreo-athetotic Cerebral Palsy, dominated by both hyperkinesia and hypotonia

4. Ataxic Cerebral Palsy is characterised by both of:

- Abnormal pattern of posture and/or movement
- Loss of orderly muscular co-ordination, so that movements are performed with abnormal force, rhythm and accuracy

Gross Motor Function Classification System

Robert Palisano, Peter Rosenbaum, Stephen Walter, Dianne Russell, Ellen Wood, Barbara Galuppi
Reference: Dev Med Child Neurol 1997; 39: 214-223
Neurodevelopmental Clinical Research Unit (NCRU)

Level I

Between the 4th and 6th birthdays: Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

Level II

Between the 4th and 6th birthdays: Children walk without the need for any assistive mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

Level III

Between the 4th and 6th birthdays: Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children walk with an assistive mobility device on level surfaces and may climb stairs with assistance from an adult. Children frequently are transported when travelling for long distances or outdoors on uneven terrain.

Level IV

Between the 4th and 6th birthdays: Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a power wheelchair.

Level V

Fra 2 år til 12-årsdagen: Physical impairments restrict voluntary control of movement and the ability to maintain anti-gravity head and trunk postures. All areas of motor function are limited.

BFMF - Bimanual Fine Motor Function

(Eva Bechung og Gudrun Hagberg, Dev Med Child Neuro. 2002 may;44(5);309-16)

Level I

One hand manipulates without restriction; other hand manipulates without limitation OR has limitations in more advanced fine motor skills.

Level II

One hand manipulates without restriction; other hand has ability only to grasp or hold OR both hands have limitations in more advanced fine motor skills.

Level III

One hand manipulates without restriction; other hand has no functional ability OR one hand has limitations in more advanced fine motor skills; other hand has ability only to grasp or worse. Child needs help with tasks.

Level IV

Both hands have ability only to grasp; OR one hand has ability only to grasp; other hand has ability only to hold or worse. Child needs support and/or adapted equipment.

Level V

Both hands have ability only to hold or worse. Child requires total assistance, even with adaptations.

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

MACS is a system to classify children's ability to handle objects in daily activities

- MACS intends to describe which level best represents the child's usual performance in home, school and community settings.
- MACS level must be determined based on knowledge about the child's actual performance in daily life. It should not be done by conducting a specific assessment but by asking someone who knows the child and how that child performs typically.
- To determine the level of MACS, the child's ability to handle objects needs to be considered from an age-related perspective.
- MACS intends to report the participation of both hands in activities, not an assessment of each hand separately.

Introduction and User Information

The purpose of the Manual Ability Classification System (MACS) is to provide a systematic method to classify how children with cerebral palsy use their hands when handling objects in daily activities. MACS is based upon self-initiated manual ability, with a particular emphasis on handling objects in an individual's personal space (the space immediately close to one's body, as distinct from objects that are not within reach).

The focus of MACS is on determining which level best represents the child's usual performance in home, school and community settings. Accordingly, the level must be determined by asking someone who knows the child well and not by conducting a specific assessment. MACS is not designed to classify best capacity and does not mean to distinguish different capacities between the two hands. MACS does not intend to explain the underlying reasons for limitations of performance or to classify types of cerebral palsy.

Distinctions between the levels are based on the child's ability to handle objects and their need for assistance or adaptations to perform manual tasks in everyday life. The objects in question are those that are relevant and age appropriate for the child, used for example in eating, dressing, playing, writing, as distinct from objects used in advanced specially skilled activities, like playing a musical instrument.

MACS can be used for children of different ages, but some interpretation is needed regarding the age of the child. Obviously, children handle different objects at four years of age, compared to when they are adolescents. The same point concerns independence, as a young child needs more help and supervision than an older child. Classification of a child should be made with reference to children of the same age.

A child's motivation and cognitive ability influence their ability to handle objects and thereby their MACS level. If the child's motivation to perform activities is low, if they do not understand the task or continuously ask for help and support from adults, they should be classified based on their actual performance, even if they are thought to have a higher capacity.

As a general principle, if a child's manual ability fits within a particular level the child will probably be classified either at or above that level. Children who do not perform the functions of a particular level will almost certainly be classified below that level. Level I includes children with cerebral palsy with, at most, minor limitations compared to typically developing children, and where the limitations, if any, barely influence their performance of daily life tasks. In MACS five levels are described. Distinctions between each pair of levels are also provided to assist in determining the level that most closely resembles a child's manual abilities.

The scale is ordinal, with no intent that the distances between levels should be considered equal, or that children with cerebral palsy are equally distributed across the five levels.

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Brochure is printed by means of Cerebral Palsy society.

What do you need to know to use MACS?

The child's ability to handle objects in important daily activities, for example during play and leisure, eating and dressing.

In which situation is the child independent and to what extent do they need support and adaptation?

- I Handles objects easily and successfully.** At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.

Distinctions between Levels I and II

Children in Level I may have limitations in handling very small, heavy or fragile objects which demand detailed fine motor control, or efficient coordination between hands. Limitations may also involve performance in new and unfamiliar situations. Children in Level II perform almost the same activities as children in Level I but the quality of performance is decreased, or the performance is slower. Functional differences between hands can limit effectiveness of performance. Children in Level II commonly try to simplify handling of objects, for example by using a surface for support instead of handling objects with both hands.

- II Handles most objects but with somewhat reduced quality and/or speed of achievement.** Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.

Distinctions between Levels II and III

Children in Level II handle most objects, although slowly or with reduced quality of performance. Children in Level III commonly need help to prepare the activity and/or require adjustments to be made to the environment since their ability to reach or handle objects is limited. They cannot perform certain activities and their degree of independence is related to the supportiveness of the environmental context.

- III Handles objects with difficulty; needs help to prepare and/or modify activities.** The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.

Distinctions between Levels III and IV

Children in Level III can perform selected activities if the situation is prearranged and if they get supervision and plenty of time. Children in Level IV need continuous help during the activity and can at best participate meaningfully in only parts of an activity.

- IV Handles a limited selection of easily managed objects in adapted situations.** Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.

Distinctions between Levels IV and V

Children in Level IV perform part of an activity, however, they need help continuously. Children in Level V might at best participate with a simple movement in special situations, e.g. by pushing a simple button.

- V Does not handle objects and has severely limited ability to perform even simple actions.** Requires total assistance.