



PRM Section & Board

## Clinical Affairs Committee

Template Version 2.3

# CEREBRAL PALSY INPATIENT (RE)HABILITATION PROGRAMME FOR CHILDREN

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# I. Summary

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**Background:** The Programme is performed in the National Rehabilitation centre „Vaivari“. The organization of the Programme is based on: National Regulation, on the White Book of Physical and Rehabilitation Medicine in Europe, on International scientific guidelines and recommendations, and on ICF –CY children and youth version.

**Target population and procedure:** The Programme is focused on children CP patients with functional disability. The patients are selected by a PRM doctor who performs the assessment of patient's functioning disorders, rehabilitation potential and indications, who designs the rehabilitation plans. They are referred to a PRM doctor by a general practitioner, a neurologist or a paediatrician.

The Programme is funded by the National Health Insurance. Safety and patient rights are defined by National regulations. Each patient signs an informed consent.

**The main goals of the Programme are:** to increase motor function level, to reduce spasticity and pain, to facilitate participation in activities of daily living and improve overall care, to prevent or reduce secondary complications, to improve communication, to evaluate necessary technical aids, and to educate family members.

**The Department permanent manpower** consists of 2 PRM specialists; 0,35 part-time PRM resident; 1-2 PRM resident; 6 physiotherapists; 2,5 occupational therapists; 1,5 psychologists; 1 social worker; 6,5 nurses; 4,5 nurse assistants; 1 nurse assistant at a pearl bath; 2,5 speech therapists, 1 music therapist; 1 secretary. Consultants from other departments and University clinics are also involved on demand. (technical orthopaedist, ophthalmologist, dermatologist, neurologist, orthopaedic surgeon, otorhinolaryngologist, gynecologist, psychiatrist). Horse riding instructors, nutritionist, dance and movement therapist are also involved in the CP rehabilitation program on demand.

**The approach** to the Programme is multi-professional. The PRM specialist has an overall leadership on the team and is "the patient's manager". He/she is responsible for the initial patient's evaluation, the setup of an appropriate strategy, the team coordination and further patient's follow-up.

**Patient's assessment** is based on the evaluation presented in the White Book on Physical and Rehabilitation Medicine in Europe, ICF-CY children and youth version. The members of the team evaluate the patient subsequently. On the basis of this comprehensive evaluation, the initial PRM strategy is adjusted and the rehabilitation plan is confirmed. It may be adapted according to patient's clinical and functional findings, after regular team meetings.

**Treatment methods** to achieve rehabilitation goals, physiotherapy, occupational therapy, psychology, speech therapy, dance and movement therapy, massage, hipotherapy, hydro complex procedures and physical modalities are used. In rehabilitation process family member who assists the child is included in the rehabilitation team. Multidisciplinary Therapy plays a vital role in managing the physical impairment while optimizing mobility. Therapy is deployed to manage impairment (primarily spasticity, contractures and muscle tone), manage pain, and provide optimum quality-of-life by fostering functionality, self-care, and independence. Therapy also yields mental, emotional, academic, and social benefits for individuals with cerebral palsy. All patient's medical and functional information, assessment and further monitoring data is recorded into a standardised medical documentation. A standardised discharge report with further recommendations is written in several copies, for the patient and for his/her GP. All the Programme documents are stored in the clinical archive and are accessible for periodic internal or external audit and outcomes assessment. Care of the child with cerebral palsy involves developing a trusting and cooperative relationship with parents. As with all children, a supportive home environment builds self-esteem and confidence. Parents may need practical support such as provision of respite care and

1 information about financial allowances, and are helped by meeting other families in similar  
2 circumstances.

3 **Long term outcomes monitoring:** patient has follow-up re-evaluation of PRM doctor 6-12  
4 months after discharge of in-patient rehabilitation centre. PRM doctor decides if the patient  
5 needs further rehabilitation and should it be done as an outpatient or in-patient rehabilitation.  
6 For children younger than 5 years the follow-up program is implemented twice a year, but  
7 for older ones – once a year.

## II. General foundations of the Programme

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### A. PATHOLOGICAL AND IMPAIRMENT CONSIDERATIONS

#### 1. *Etiology*

Cerebral palsy is thought to have multifactorial aetiology. (4) In most cases, neuroimaging shows brain abnormalities. (5; 7) The majority are attributable to disturbances of intrauterine brain development. (6) Cerebral palsy is a well recognized neurodevelopment condition beginning in early childhood and persisting through the lifespan. (8)

Current views upon the aetiology comprise an underlying structural abnormality of the brain; early prenatal, perinatal, or postnatal injury due to vascular insufficiency; toxins or infections; or the pathophysiologic risks of prematurity. Such factors as preterm birth, multiple gestation, intrauterine growth restriction, male sex, low Apgar scores, intrauterine infections, maternal thyroid abnormalities, prenatal strokes, birth asphyxia, maternal methyl mercury exposure, and maternal iodine deficiency may also contribute to the development of this condition. (1)

#### 2. *Natural history and relationship to impairment.*

Cerebral palsy may present multiple tonal abnormalities and the presence of primitive reflexes. The positive motor signs or involuntary motricity include hypertonia (spasticity, dystonia and rigidity) and hyperkinesia (dystonia, chorea, athetosis, myoclonus, tremor, tics, and stereotypies). Negative motor signs characterised by deficient muscle control and may appear as weakness, reduced selective motor control, ataxia, and apraxia. Neonate after a severe brain injury usually has hypotonia, difficulty to elicit muscle stretch reflexes, delayed milestones, spasticity developing over time. (4)

There are several types of cerebral palsy.

**Spastic cerebral palsy** has at least two of the following characteristics: abnormal pattern of posture and/or movement, increased tone (not necessarily constant) and pathological reflexes (hyperreflexia and/or pyramidal signs). (11) Patients with spastic cerebral palsy constitute the majority (75%) of patients with cerebral palsy. (1) It is subsequently classified according to topography of abnormal motor function. Diplegic pattern shows the involvement of both lower extremities, hemiplegic – of lower and upper extremity unilaterally, triplegic – of three extremities, usually two lower and one upper, and quadriplegia/tetraplegia – of four extremities. (12)

Hemiplegic cerebral palsy usually presents with one-sided upper motor neuron deficit, where arm generally affected more than leg; early hand preference or relative weakness on one side; gait possibly characterized by circumduction of lower extremity on the affected side, specific learning disabilities, oromotor dysfunction, possible unilateral sensory deficits, visual-field deficits, strabismus and seizures. (1) Spastic diplegic pattern is characterised by upper motor neuron findings in the legs more than the arms, scissoring gait pattern with hips flexed and adducted, knees flexed with valgus, and ankles in equinus, resulting in toe walking. Learning disabilities and seizures are less common compared to spastic hemiplegia. (1) In case of spastic quadriplegic cerebral palsy all limbs are affected, either full-body hypertonia or truncal hypotonia with extremity hypertonia is present. These children usually have oromotor dysfunction, increased risk of cognitive difficulties, multiple medical complications, seizures, legs generally affected equally or more than arms. (1)

**Diskynetic cerebral palsy** is characterised by abnormal pattern of posture and/or movement coupled with involuntary, uncontrolled, recurring, occasionally stereotyped movements. (11) Stress or purposeful activity may increase abnormal movement patterns. Muscle tone during sleep usually is normal. There is high incidence of sensorineural hearing loss and pseudobulbar involvement. Therefore the condition often presents with dysarthria, swallowing difficulties, drooling, oromotor difficulties, and abnormal speech patterns. Classically the patient presents with early hypotonia with movement disorder emerging at

age 1-3 years where arms are more affected than legs, deep tendon reflexes usually normal to slightly increased, there is some spasticity, oromotor dysfunction, gait difficulties, truncal instability, and the risk of deafness in those affected by kernicterus. (1) It is further subdivided into two types: dystonic pattern combines hypokinesia and hypertonia, while choreo-athetotic pattern – hyperkinesia and hypotonia. (11)

**Ataxic cerebral palsy** demonstrates abnormal pattern of posture and/or movement combined with loss of orderly muscular coordination with disturbances of movement force, rhythm and accuracy. (11)

Children may present with **hypotonic cerebral palsy** that is considered to be a rare type. (33, 34) It often has leg weakness, while the arms manifest near-normal strength and coordination.

**Mixed cerebral palsy** combines both spastic and extrapyramidal types with ataxic component frequently present. (34)

Severity of limitations is classified into five levels using **Gross Motor Function Classification System** (GMFCS), where level I is assigned to children walking independently, II – to those who walk with limitations, III – to those who walk using a hand-held mobility device, IV – to those with limited self-mobility and using powered mobility, and V – to children transported in a manual wheelchair. (4)

**There is a spectrum of impairments that accompany the condition.** The most common are dysphagia, malnutrition, an increased risk of aspiration events, lung disease, epilepsy, intellectual disability, vision and hearing deficits, voiding dysfunction, gastroesophageal reflux disease (GERD), constipation, musculoskeletal pain and osteopenia. (4) Chronic pain is present in up to 75% of children with cerebral palsy. (9, 43) The causes may be related to muscle spasm or strain, orthopedic issues, undetected dental caries, skin breakdown, constipation, gastroesophageal reflux and other reasons. (43) 1 in 2 children with cerebral palsy has intellectual disability. (43) Hip disorders are present in 28% of cases, with greater risk of hip displacement in children with Gross Motor Function Classification Scale (GMFCS) level III-V. (41, 43) Approximately 23% of children with cerebral palsy cannot communicate verbally. (43) Behavior disorders are present in 25% of cases (9). Behavioural and psychologic complications may include attention-deficit/hyperactivity disorder, depression, autism and the impact on self-esteem. (1) 15-60% of children with cerebral palsy have epilepsy, and it is more common in patients with spastic quadriplegia. (1) Approximately 25% of children have bladder incontinence. (9) 20% suffer from sleep disorders. (9) Oropharyngeal dysphagia is present in 85% of children 18-36 months corrected age and 1 in 15 children with cerebral palsy requires non-oral feeding. (9, 42) In 10% of cases blindness is present and 4% of children with cerebral palsy cannot hear (9).

**Abnormal MRI** (magnetic resonance imaging) neuroimaging patterns may show periventricular white matter injury, diffuse grey matter injury, cerebral vascular accident, cerebral malformation, intracranial haemorrhage, infection and non-specific radiologic findings. Normal imaging results are also possible. (10)

### 3. *Diagnosis approach and prognosis*

The diagnostic approach of cerebral palsy is based on thorough history taking on possible risk factors, neurologic and motor development assessment, brain MRI neuroimaging, and exclusion of alternative diagnoses. (4, 9)

Neuroimaging studies are recommended if aetiology is not clear. MRI is preferred to CT imaging. Metabolic and genetic testing is considered if there is no evidence of structural abnormality on neuroimaging, or the patient presents additional or atypical features on history taking or clinical assessment, or neuroimaging reveals a brain malformation. For patients with hemiplegic cerebral palsy coagulation studies should be considered. If there are suspicions about presence of epilepsy or an epileptic syndrome, electroencephalography should be ordered.

Patients with cerebral palsy should be evaluated on mental retardation, ophthalmologic and hearing impairments, and speech and language disorders. (13) On first orthopaedic visit hip

1 and pelvic radiographs should be obtained, follow-up radiographs are ordered depending on  
2 the severity of involvement. (14)

3 Cerebral palsy is a life-long condition. Aging occurs earlier, but majority has normal life  
4 expectancy. Poorer prognosis is associated with epilepsy and intellectual disability combined  
5 with severe physical disability.

6 **Walking prognosis** : Sixty percent of children will walk independently, ten percent will be  
7 aided, and thirty – wheelchair users. Ability to sit independently by the age of two years or  
8 having less than three primitive reflexes by the age of 18 to 24 months is associated with  
9 better outcome, while inability to sit by 4 years – with worse prognosis for ambulation.  
10 Unilateral injuries and periventricular white-matter lesions are associated with better  
11 prognosis, while brain malformations, cortical, subcortical and basal ganglia injuries – with  
12 poorer. (4, 9)

13 Thirty to fifty percent of children with cerebral palsy have **mental retardation**, and some form of  
14 learning disability is present in approximately 75% of patients. (1) Approximately 23% of children  
15 with cerebral palsy are unable to communicate verbally. (43)

16 Outcome is also influenced by **comorbidities** that may accompany the disorder. GMFCS  
17 can also serve as a predictor of longitudinal gross motor function, where GMFCS levels I and  
18 V generally remain as the child grows, while GMFCS levels II, III and IV are often reclassified.  
19 (4, 9)

#### 20 **4. Impairment treatment principles**

21 Cerebral palsy is the commonest physical disability in childhood seen in practice by  
22 rehabilitation professionals (1) Data from studies confirm that early diagnosis and therapeutic  
23 intervention lead to improvement in skills of children with cerebral palsy and mental  
24 retardation and implicitly a better life quality. The approach of these children problems in a  
25 multidisciplinary team is determinant for obtaining better performances. (2)

26 Professionals in paediatric rehabilitation are faced with a diversity of problems in the child  
27 and family (physical, psychological, communicative, and social), so a multidisciplinary  
28 approach for treatment is needed (3)

29 With early and ongoing treatment, the effects of CP can be reduced. Many children learn  
30 how to get their bodies to work for them in other ways. (16)

31 The condition is treated by a multidisciplinary team that is composed according to the child's  
32 needs. (4) Primary medical coordinator manages the team and ensures proper  
33 communication between professionals.

34 Children with CP may need different kinds of therapy, including:

35 •Physical therapy (PT), which helps the child develop stronger muscles such as those in the  
36 legs and trunk. Through PT, the child works on skills such as walking, sitting, and keeping  
37 his or her balance. (16) Physical therapist works on gross motor skill improvement, does  
38 strengthening, stretching exercises, and determines the necessity for mobility devices. (7)

39 •Occupational therapy (OT), which helps the child develop fine motor skills such as dressing,  
40 feeding, writing, and other daily living tasks. (16) Occupational therapists concentrate on  
41 upper-extremity functions and evaluate the necessity to use adaptive technologies and  
42 equipment. (7)

43 •Speech-language pathology (S/L), which helps the child develop his or her communication  
44 skills. The child may work in particular on speaking, which may be difficult due to problems  
45 with muscle tone of the tongue and throat. (16) Speech and language therapists work on  
46 language skills' improvement, evaluate articulation, oromotor deficits, and the necessity to  
47 use communication systems. (7)

48 All of these are available as related services in both early intervention programs (for very  
49 young children) and special education (for school-aged children). (16)

50 Prescription of durable medical equipment is important for individuals with cerebral palsy  
51 since it is able to maximise function, improve safety, enable independence and foster



cognitive development through enabling better exploration of the environment. (4) For example, braces (also called AFOs) may be used to hold the foot in place when the child stands or walks. Custom splints can provide support to help a child use his or her hands. A variety of therapy equipment and adapted toys are available to help children play and have fun while they are working their bodies. (16)

Spasticity-reducing treatment options include physical therapy, orthoses, casting, oral medications such as Baclofen, chemodenervation with botulinum toxin, as well as neurosurgical procedures including intrathecal baclofen (ITB), Deep Brain Stimulation (DBS) and selective dorsal rhizotomy (SDR). (4)

In some cases orthopaedic surgery may be required with the necessity to perform muscle releases and lengthening's, tendon transfers, osteotomies and arthrodesis. Such conditions as scoliosis, hip displacement and contracture management typically are addressed. (4, 6)

Activities such as swimming or horseback riding can help strengthen weaker muscles and relax the tighter ones. (16) There is evidence supporting the ability of hippotherapy to improve gross motor function, as well as hip and trunk symmetry and stability. (15)

For school-aged children, including pre-schoolers, special education and related services will be provided through the school system. (16)

New medical treatments are being developed all the time. Sometimes surgery, Botox injections, or other medications can help lessen the effects of CP, but there is no cure for the condition. It's also important to understand that cerebral palsy is not contagious, not inherited, and not progressive. The symptoms will differ from person to person and change as children and their nervous systems mature. (16)

## B. ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS

ICF-CY Children and Youth version codes from Chapter activities and participation d110-d820; d835-d839; d920-d940.

## C. SOCIAL AND ECONOMIC CONSEQUENCES

### 1. *Epidemiological data*

In Latvia, every year, there are about 40 new cases of CP. According to the Surveillance of Cerebral Palsy in Europe (SCPE) the incidence in Europe is 2 per 1000 live births. The incidence is higher in males than in females with male to female ratio of 1.33:1.

The prevalence in Europe and Australia ranges from 35.0 to 79.5 per 1,000 live births for children born at 28 to 31 weeks of gestation. The figures are 1.1 to 1.7 per 1,000 live births for children born at 37 or more weeks of pregnancy. Of all children with cerebral palsy in the United Kingdom, 91% have spastic cerebral palsy. Nearly one third of children in addition have severely impaired lower limb function or leg function. Nearly a quarter of all individuals with cerebral palsy have severely impaired upper limb function. There are variations depending on geographical location.

The SCPE reported from data between 1980–1990 among 4,500 children over age 4 whose CP was acquired during the prenatal or neonatal period that 31% had an intellectual disability (IQ lower than 50), 21% had epilepsy and active seizures, 20% had IQ lower than 50 and were not walking and 11% had blindness. (17-21)

### 2. *Social data*

Children with all levels of disability are eligible to receive a rehabilitation course. In Latvia, most of the cases, nursing of CP children in family is done by their mother and they are not able to work employed job.

1           **3. Economic data**

2           The government in Latvia provides the allowance to the family state benefit for a child with  
3           disabilities in the amount of 106,72 euro. If a person has a severe functional impairment, and  
4           there is a necessity of special care, additional allowance of 213,43 euro is provided. In some  
5           cases the allowance to compensate transport expenses of persons with mobility disabilities  
6           is granted, the amount of which is 79,68 euro for each six month period. (44)

7           No data are accessible for one CP patient costs in the country.

8

9           **D.LEGAL FRAMEWORK**

10

11           First treatment for newly diagnosed patients lasts for 14-21 days in inpatient rehabilitation  
12           programme.

13           The follow-up program can be implemented on an in-patient, out-patient or day hospital  
14           basis. The follow-up program for inpatients lasts for 14-21 days. For children younger than 5  
15           years it is realized twice a year, but for older ones – once a year.

16           Patients' rights are guaranteed in Constitution of the Republic of Latvia: "The State will  
17           protect human health and guarantee a basic level of medical assistance for everyone". (22)  
18           Rehabilitation programme for CP patients in National Rehabilitation centre "Vaivari" is  
19           financed by state.

20

21

22

### III. Description of the Programme

#### A. ENVIRONMENT OF THE PROGRAMME

##### 1. Clinical setting

Individual practice or part of a doctor's group practice	Yes/No
Individual practice in a private hospital	Yes/No
Part of a local (public) hospital	Yes/No
Part of a regional hospital (or rehabilitation centre)	Yes/No
Part of a university or national hospital	<b><u>Yes</u></b>

Comment:

##### 2. Clinical programme

Inpatients in beds under PRM responsibility	<b><u>Yes</u></b>
Inpatient beds belonging to other departments	Yes/No
Day programme (most of the day in outpatient setting, not home)	Yes/No
Outpatient clinic (assessment and/or treatment, for up to 3 hours/day)	Yes/No
Community based (in the patient's home or workplace or other relevant community location, eg sports centre)	Yes/No

Comment: There are inpatients beds for newly patients and follow up programme, beds for parents.

##### 3. Clinical approach

Uniprofessional	Yes/No
Multiprofessional	<b><u>Yes</u></b>

Comment: with involvement of necessary specialists-consultants form other center's programs and University clinics.

##### 4. Facilities

Does your programme have a designated space for:	
For assessments and consultations?	<b><u>Yes</u></b>
For an ambulatory or day care programme?	<b><u>Yes</u></b>
For inpatient beds?	<b><u>Yes</u></b>
For therapeutic exercises?	<b><u>Yes</u></b>
For training in independence and daily living?	<b><u>Yes</u></b>

For vocational and/or recreational activities?	<b><u>Yes</u></b>
--	-------------------

1 Comment:

2 There are facilities for inpatient beds (40 beds for patients and 30 for family members),  
3 consulting rooms for physicians, halls for therapeutic exercises, rooms for training in  
4 independence and daily living, vocational and recreational activities, art teaching and music  
5 therapy class, speech therapy complex, consulting rooms for psychologists and a social  
6 worker, specially equipped room for sensory stimulation, room for a pearl bath.

7 There is accessibility to fitness gym, hydrotherapy complex and swimming pool, horse riding  
8 therapy arena, physical modalities complex, dance and movement therapy class, intensive  
9 therapy unit with anaesthesiologist on 24-hour duty.

## 12 B. TARGET POPULATION

### 13 1. *Inclusion criteria*

- 14 • Children (till 18 years of age) with CP diagnosis.
- 15 • A patient is admitted as soon as he/she is medically stable.

### 17 2. *Criteria for refusal*

- 18 • Patient's functional disorders not related to CP (for example, metabolic syndromes,  
19 genetic syndromes).
- 20 • Patients with CP diagnosis older than 18 years of age.
- 21 • Severe and/or decompensated comorbidities or complications.

### 23 3. *Patients referrals*

24 Direct access to the PRM programme	Yes/No
Referral from general practitioners	Yes/No
Referral from other specialists	Yes/No
Referral from specialists in PRM	<b>Yes</b>

25 Comment: GP or other specialists forward patient to PRM physician for consultation, and  
26 he/she takes a decision on the selection of a rehabilitation setting. PRM specialists are in  
27 acute hospital settings or they can consult the patient ambulatory.

### 29 4. *Stage of recovery before admission*

30 Within two weeks of onset	<b><u>Yes</u></b>
2 weeks to 3 months after onset	<b><u>Yes</u></b>
3 months or longer after onset	<b><u>Yes</u></b>

31 Comment: A patient is admitted into the post-acute program as soon as he/she is medically  
32 stable and has no complications.

1 Long-term follow-up program is usually carried out once or twice a year for patients who have  
2 received a first rehabilitation course. PRM specialist makes individual rehabilitation plan. For  
3 children younger than 5 years the follow-up program is implemented twice a year, but for  
4 older ones – once a year.

5

## 6 **5. Early management before admission**

### 7 **A) How are patients selected ?**

8 Early diagnosis and assessment performed in the hospital both by a neurologist and a PRM  
9 doctor. The patient can be referred to a PRM doctor by a general practitioner, a paediatrician  
10 or a neurologist. The PRM doctor performs the assessment of patient's functioning disorders,  
11 rehabilitation potential and indications, designs the rehabilitation plans in the hospital and for  
12 further rehabilitation, and manages the transfer of the patient to the rehabilitation centre.

13

### 14 **B) Do they benefit from PRM advice in acute settings ?**

15 At the University Clinics, specialized and regional hospitals the PRM services are accessible  
16 where patients are consulted and the rehabilitation course has been started in the acute  
17 stage and then the patient is sent for further rehabilitation within a specialized programme.

### 18 **C) What alternate solutions are proposed to refused patients ?**

19 The refused patients continue the medical treatment and the stabilization of health conditions  
20 in the hospital. They take treatment of comorbidities and complications in the hospital setting.  
21 Then, they are oriented to palliative care programme, Social Care Centre without intensive  
22 rehabilitation or they return back home where they are under the care of their general  
23 practitioner and their family. Family members are thought how to care for the patient, to  
24 reduce complications.

25

26

## C. GOALS

Main goals of the programme are:

- to increase motor function level
- to reduce spasticity and pain
- to facilitate participation in activities of daily living and improve overall care
- to prevent or reduce secondary complications
- to improve communication
- to evaluate necessary technical aids
- to educate family members.
- In terms of body structure and body function (impairment)
- to use ICF child and youth version in professional communication. (39)

ICF code	ICF label
	<b>Impairment of body functions</b>
b114	Orientation functions
b139	Global mental functions
b140	Attention functions
b144	Memory functions
b152	Emotional functions
b156	Perceptual functions
b164	Higher level cognitive functions
b167	Mental functions of language
b235	Vestibular functions
b399	Voice and speech functions, unspecified
b4459	Respiratory muscle functions, unspecified
b5105	Swallowing
b5253	Faecal continence
b620	Urination functions
b710	Mobility of joint functions
b 730	Muscle power functions
b735	Muscle tone functions
b770	Gait pattern functions
	<b>Impairment of body structure</b>
s110	Structure of brain
s120	Spinal cord and related structures
s398	Structure involved in voice and speech
s710	Structure of head and neck region
s730	Structure of upper extremity

s730	Structure of lower extremity
s760	Structure of trunk

Comment:

1  
2  
3  
4  
5

**1. In terms of activity**

ICF code	ICF label
d1	All codes of chapter 1: d110-d179 Learning
d3	All codes of chapter 3 Communication
d4	All codes of chapter 4 Mobility
d5	All codes of chapter 5 Self Care
d8	All codes of chapter 8 Education

6  
7  
8  
9

**2. In terms of participation**

ICF code	ICF label
d920	Recreation and leisure
D930	Religion and spirituality
D940	Human rights

10  
11

## D. CONTENT OF THE PROGRAMME

### 1. *General scheme and time frame*

CP patients in acute phase have usually been admitted to neurological department of University or regional hospitals. Rehabilitation has usually been started in an acute setting. Then the process continues in the specialized CP rehabilitation programme of NRC "Vaivari".

Lengths of stay for CP patients are 14-21 days.

The average time patients spend in therapy 3-4 hours a day.

The follow up is usually implemented once/twice a year after the first rehabilitation course.

### 2. *Role of PRM specialist*

The PRM specialist:

- examines the patient, uses specialised assessment tools (GMFCS, goniometry, muscle strength test, modified Ashworth scale, Tardieu scale, Viking speech scale, Visual analogue scale of pain)
- has overall responsibility and direction of the multiprofessional team and rehabilitation programme, sets short and long term goals and works out the rehabilitation plan, organises meetings of the multidisciplinary rehabilitation team once a week,
- applies medical and physical treatments and treats comorbidity and secondary complications, including Botulin toxin injections to reduce spasticity,
- evaluates the rehabilitation outcome, makes a prognosis of the condition and communicates this message to family members,
- invites necessary consultants and organizes medical joint meetings for complicated cases.
- educate patients and caregivers about prevention of secondary complications.

### 3. *Specific role of each team member in this programme*

The rehabilitation team, led by a PRM doctor, sets the rehabilitation goals.

Maximal functional independence allows decreasing the restrictions in activities, participation and the influence of environmental factors. Goals will be achieved by training and re-training different skills. The functions of the rehabilitation specialists overlap in certain segments and thus allow achieving the main goal successfully in various ways – the good quality of life possible despite the impairment.

Care of the child with cerebral palsy involves developing a trusting and cooperative relationship with parents. As with all children, a supportive home environment builds self-esteem and confidence. Parents may need practical support such as provision of respite care and information about financial allowances, and are helped by meeting other families in similar circumstances. (23)

**Physiotherapists** will develop mostly gross motor skills and mobility: bed mobility, transfers mobility, wheelchair mobility, walking ability, gait training and the functions of the upper and lower extremities, reduce muscle misbalance, stimulate development according to the age.

Physiotherapists work with different techniques:

1. Approximation.
2. Proprioceptive neuromuscular facilitation
3. Post-isometric relaxation.



- 1 4. Bobath therapy.
- 2 5. Correct manual handling principles.
- 3 6. Traction.
- 4 7. Postural drainage, breathing exercise.
- 5 8. Kinesiotaping.
- 6 9. Joint game
- 7 10. Positioning the Patient.
- 8 11. Passive movements.
- 9 12. Muscle strength exercise.
- 10 13. Stretching techniques.
- 11 14. Isometric exercise.
- 12 15. Relaxation techniques.

13 Physiotherapists are responsible for evaluation of motor function including voluntary and  
 14 involuntary motor activity of all muscle groups, spasticity assessment, training for range of  
 15 motion, walking and standing, balance ,hip surveillance, orthotic/bracing intervention  
 16 adaption, active motor training, respiratory rehabilitation, treadmill walking with body weight  
 17 support, physical modalities, activities in swimming pool. Giving out education materials.  
 18 Evaluation according GMFM 66, GMFM 88

### 19 **Occupational therapists**

- 20 1. Positioning using assistive devices to facilitate or/and involve in activity:
- 21  Activity chairs;
- 22  Wheelchairs;
- 23  Verticalisation devices;
- 24  Bath chairs;
- 25  Special chairs for cars (24);
- 26 2. Neurodevelopmental therapy Emphasis of treatment is to promote function with
- 27 improved alignment and tonal normalization along with weight shifting and postural activation
- 28 in both movement through space as well as in postural holding activities (15, 25).
- 29 3. Contracture prophylaxis. (26, 27)
- 30 4. Active or functional therapy approaches (This therapeutic approach involves actively
- 31 practicing real-life tasks, typically in real-life environments, for the purpose of gaining skills
- 32 that are important to the child and the family). (15)
- 33 5. Improving hand function (28)
- 34 6. Constraint – inducted movement therapy (25)
- 35 7. Intensive bimanual training (motorlearning-based approaches that focus on upper limb
- 36 (UL) function in children with hemiplegic CP (28).
- 37 8. Wrist– hand orthoses (static and functional) (29).

38 Occupational therapists provide training of participation in activities of daily living and upper  
 39 limb function and hand fine motor skills retraining, involve in special equipment prescription  
 40 and environmental modification, new techniques and use special equipment for achieving  
 41 these goals. Occupational therapists determine the necessity of different types of assistive  
 42 technology. They also organize recreational activities.

43 **The speech and language therapist** works on communications skill development,  
 44 improvement, and diversity. He checks if the child with cerebral palsy can communicate only  
 45 emotionally, if he uses random sounds or words, or if he uses any of other alternative

1 communication methods such as sign language and gesture. If language skills aren't verbal,  
 2 the speech therapist evaluates the most appropriate alternative speech development  
 3 method. If communication is verbal, therapist evaluates the clarity of speech,  
 4 comprehensibility, and sound pronunciation. To improve the clearness of speech, he works  
 5 on correct sound pronunciation, sound differentiation and automation. For children with  
 6 cerebral palsy is common to perform breathing and voice disorder correction by speech  
 7 therapist; that strengthens breathing and voice apparatus performance, using various  
 8 breathing, blowing, and phonation exercises. The child can have defective rhythm of speech  
 9 or speed; to correct that the therapist uses personalized rhythmic game methods.

10 Because vision functionality plays an important role developing child's speech, a speech  
 11 therapist quite often works on training and developing hearing and vision functionality. (35)  
 12 He offers exercises to improve and develop the fine motility skills. A speech therapist works  
 13 to evaluate problems with swallowing and to prevent them. To activate articulation apparatus  
 14 performance, he can use various articulation apparatus exercises and orofacial therapy. (36)  
 15 To test cerebral palsy of child's speech, useful is Viking Speech Scale. It is used for children  
 16 starting of age of 4. This scale has 4 levels that classify child's daily speech. (37)

### 17 **Psychologists:**

18 Help an individual develop life skills, such as the ability to manage stressful situations or  
 19 events that result in anger or frustration, or that lead to negative outcomes, such as isolation,  
 20 rejection, low performance, attention deficit, or social-emotional deficiencies. Psychologists  
 21 help with learning disabilities with intellectually impaired individuals. (30)

22 Psychologists work with sand therapy. This form of therapy is used, to discover the interests  
 23 of the child, tap into their emotions, release irrational thoughts and fears and help the child  
 24 express their emotions through play. Play therapy also allows the child to feel more  
 25 comfortable with the therapist and therefore opens doors for better communication. (31)

26 Used assessment tools: WISC-IV test.

### 27 **Social workers:**

28 Advice and help in social security fields, cooperation with the family and local municipalities  
 29 about financial support, house adaptation, include to school or kinder garden.

30 **Music therapists** use instrumental and vocal music activities, designed to reduce pain and  
 31 anxiety, manage stress, improve communication and emotional expression. (38)

32 **The nursing staff** provide tips for parents, estimates the amount of medical care needed  
 33 and the risk of development of pressure ulcers. For example, they advice to learn about CP,  
 34 to love and play with the child, to learn from professionals and other parents how to meet the  
 35 child's special needs, but try not to turn their lives into one round of therapy after another, to  
 36 keep informed about new treatments and technologies that may help, to learn about assistive  
 37 technology that can help the child, to be patient and keep up their hope for improvement.  
 38 (16)

39 Nurses are responsible for positioning in bed. They teach patients to perform everyday life  
 40 skills. Nursing staff often has close interactions with family members.

### 42 **Additional consultants and therapists:**

#### 43 **Nutritionists**

44 Consult about energy needs, protein needs, ideal body weight, fluid needs, and fibre needs,  
 45 eating and swallowing disorders (malnutrition).

#### 46 **Riding therapy**

47 Is built on the concept that the individual and variable gait, tempo, rhythm, repetition and  
 48 cadence of a horse's movement can influence human neuromuscular development in  
 49 humans. Horseback riding triggers a series of complex physical and mental reactions; such  
 50 as making physical adjustments to maintain proper alignment on the horse. Riders must also  
 51 plan movements to maintain balance on the horse, and be able to interact with the animal.

Riding therapy, through equine movement, works by further developing physical and cognitive abilities, including:

- Strength
- Control
- Balance
- Posture
- Endurance
- Coordination
- Sensory integration
- Understanding of visual cues

Hippo therapy can help children with cerebral palsy on several fronts. Interacting with the animal can lift a child's spirits emotionally and psychologically while also providing valuable physical exercise as the child learns how to ride the horse properly. A horse's gait has three-dimensional movement—equine movement—similar to a human that helps a child plan physical responses to the horse's movement. Horseback riding requires subtle adjustments and positioning to maintain proper balance and posture.

Physical benefits include:

- Improved gross motor skills
- Trunk core strength
- Control of extremities
- Improved postural symmetry
- Reduced abnormal muscle tone
- Respiratory control

Cognitive benefits include:

- Improved attention
- Visual coordination
- Sensory input
- Tactile response
- Improved timing and grading of responses
- Improved ability to express thoughts, needs

Psychological benefits include:

- Enjoyable interactions with the animal
- Opportunities for social interaction
- Improved self-esteem (32)

#### **4. Diagnostic and assessment tools**

Diagnostic facilities:

- X-ray,
- Ultrasonography,
- EKG,
- EEG,

- 1 • Clinical laboratory,
- 2 • Equipped video gait analysis,
- 3 • Spirometer, peak flow meter.
- 4 Assessment tools:
- 5 • Gross Motor Function Classification System (GMFCS)
- 6 • Manual Ability Classification System (MACS)
- 7 • Gross Motor Function Measure (GMFM-66, GMFM-88)
- 8 • Ashworth scale
- 9 • Tardieu scale
- 10 • Visual analogue scale of pain
- 11 • Viking speech scale (2010)
- 12 • Muscle strength test
- 13 • Functional Independence Measure (FIM) for children
- 14 • Munich functional development diagnostics
- 15 • WISC-IV
- 16 • ICF child and youth version

## 17 **E. DISCHARGE PLANNING AND LONG TERM FOLLOW UP**

### 18 **1. Discharge criteria**

19 Patient discharge is after 14-21 days, when short term rehabilitation goals are completed,  
20 and long term rehabilitation goals are established.

21

### 22 **2. How patients are managed after the programme?**

23 After patients are discharged patients are observed by general practitioner and depending  
24 on functional disability they are monitored by neurologist, orthopaedist, oculist and other  
25 specialists. Patients continue the rehabilitation on the outpatient basis using the services  
26 available near the place of residence with emphasis made on physiotherapy, occupational  
27 therapy and speech and language therapy.

28 Patients are managed after the programme depending on the degree of functional disability.  
29 Children with a gross motor function classification system (GMFCS) level IV and V need to  
30 be evaluated more often than those with GMFCS I, II and III. Depending on the degree of  
31 involvement, regular hip and spinal x-rays are required to monitor for hip subluxation or the  
32 progression of scoliosis. General health and psychological issues are addressed including  
33 growth and weight gain rates. Any changes in neurologic condition are monitored, medical  
34 therapy and technical aids are adjusted and the necessity of surgical therapy is evaluated if  
35 necessary. (40)

36 Depending on their functional and intellectual condition, children attend regular schools and  
37 kindergartens, schools with individually adjusted programmes, special schools and  
38 kindergartens, or are home educated. It is essential that parents are made aware of all  
39 available options.

40

41

## IV. Additional information about PRM organization

### A. SAFETY AND PATIENT RIGHTS

#### 1. Safety

<b>The safety concerns of people in the unit where the programme takes place, relate to:</b>	
Emergencies (fire, assault, escape)	Yes
Medical emergencies	Yes
Equipment	Yes
Handling of materials	Yes
Transports	Yes
<b>The safety of people in the programmes of your unit is provided by:</b>	
Written standards from National Safety Bodies	Yes
Written standards from National Medical Bodies	Yes
Unit-specific written rules	Yes
Periodic inspection	
Internal	Yes
External	Yes

#### 2. Patient rights

Has your programme adopted a formal policy or statement of patients' rights?	Yes
Does this statement specify the influence that the patient should have in the formulation and implementation of the programme?	Yes
Is the statement known to all personnel involved in delivering the programme?	Yes
Is this checked periodically?	Yes
Is the statement made known to and is available to all persons visiting your unit?	Yes

#### 3. Advocacy

Give at least one example of how your organization advocates for people your programme deals with:

2009/2010 EEA and Norway grant project National multifunctional support centre for children with special needs in Vaivari.

Comment: Within the framework of the above mentioned project a working programme for the Centre was developed and Methodological guidelines for children early functional evaluation for Latvian physicians were prepared.

#### 4. PRM Specialists in the Programme

Does your PRM physician have overall responsibility and direction of the multiprofessional team?	Yes
Does your PRM physician have overall responsibility and direction of the rehabilitation programme, not medical responsibility only?	Yes
Does he/she have a European Board Certification in PRM?	Yes
Does he/she meet National or European CME/CPD Requirements?	Yes
Number of CME or EACCME points earned in the last 3 years:	350 National credit points
<b>The two primary functions for the PRM specialist in your Programme are to:</b>	
Treat comorbidity	Yes/No
Assess the rehabilitation potential of the patient	Yes
Analyse & treat impairments	Yes/No
Coordinate interprofessional teams	Yes

Comment:

Beside the two primary functions of PRM physicians, a lot of work must be done in the treatment of comorbidity and secondary complications.

The National recertification procedure on PRM specialists takes place every 5 years and requires a minimum of 250 credit points

#### 5. Staff devoted to this programme

Please, don't mention staff members who do NOT participate in this specific programme!

<b>Which rehabilitation professionals work on a regular basis (minimum of once every week) in your programme? (give the number)</b>	
PRM doctor	2
Part-time PRM resident	0,35
PRM resident	1-2
Physiotherapists	6
Occupational therapists	2,5
Psychologists	1,5
Speech & Language therapists	2,5
Social workers	1
Music therapist	0,5

Nursing staff	6,5
Nurse assistants	4,5
Nurse assistant at a pearl bath	1
Secretary	1

1 Comment:

2 Consultants from other departments and University clinics are also involved on demand.  
3 (technical orthopedist, ophthalmologist, dermatologist, neurologist, orthopedic surgeon,  
4 otorhinolaryngologist, gynecologist, psychiatrist)

5 Horse riding instructors, nutritionist, dance and movement therapist are also involved in the  
6 CP rehabilitation program on demand.

7 For children who stay in the Centre more than 14 days, a teacher is provided.

## 9 **6. Team management**

<b>How often does your staff receive formal continuing education (mark as is)?</b>	
In team rehabilitation:	<b>Not regularly</b>
In their own profession:	<b>Every year</b>
<b>Do team activities in your rehabilitation programme include the following?</b>	
Is the patient at the centre of a multiprofessional approach?	Yes
Do you always give informed choices of treatment?	Yes
Do you regularly promote family involvement?	Yes
<b>Does your organisation of multi professional team working include:</b>	
Holding regular team meetings with patient's records only (more than 2 members)	Yes
Holding regular team meetings (more than 2 members) with the presence of the patients	Yes
Joint assessment of the patient or joint intervention	Yes
Regular exchanges of information between team members	Yes

11 Comment:

12 Meetings of the multiprofessional rehabilitation team in patient's absence take place once a  
13 week.

## 14 **B. INFORMATION MANAGEMENT**

### 15 **1. Patient records**

<b>Do the rehabilitation records have a designated space within the medical files?</b>	Yes
<b>Do you have written criteria for:</b>	
Admission	Yes
Discharge	No

<b>Do your rehabilitation plans include written information about aims and goals, time frames and identification of responsible team members?</b>	Yes
<b>Do you produce a formal discharge report (summary) about each patient?</b>	Yes

1 Comment:

2  
3 Each patient has his or her own medical file, which contains information on all rehabilitation  
4 courses (first and follow up).

5  
6  
7  
8 **2. Data about general organization**

9

<b>How many new patients (registered for the first time) are treated in your programme each year:</b>	...
<b>In your day care or inpatient programme:</b>	
What is the mean duration spent in therapy by patients on this programme	14 Days
How many hours a day do the patients spend in therapy.	4 Hours
<b>Give the mean duration of stay spent in the programme:</b>	18 Days

10 Comment:

11  
12 **3. Programme monitoring and outcomes**

13

<b>Does your programme have an overall monitoring system in addition to patient's records?</b>	No
<b>Are the long term outcomes of patients who have completed your programme regularly monitored?</b>	
Impairment (medical) outcomes:	Yes
Activity/Participation (ICF) outcomes:	Yes
Duration of follow up of the outcomes:	3-6 months 12 months <b>longer</b>
<b>Do you use your outcome data to bring about regular improvements in the quality of your programme's performance?</b>	Yes
<b>Do you make the long term overall outcomes of your programme available to your patients or to the public?</b>	No

14 Comment:

15 Patients are followed-up after discharge every year. They undergo a control examination by  
16 a PRM physician.

17 Adequacy of the prescribed medical technical aids is checked.



1 Sustainability of the programme:

2

<b>Does your programme show evidence of sustainability?</b>	
Established as part of public service:	Yes/No
Has existed for more than 3 years:	Yes
Has received national accreditation (where available):	No
Has been accepted for oral presentation in a National or International congress (mandatory criterion for accreditation)	No ??
Has been the subject for papers in PRM journals	No

3

Comment: There is no national accreditation procedure for treatment programmes in Latvia.

## V. Quality improvement

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### A. WHAT ARE THE MOST POSITIVE POINTS OF YOUR PROGRAMME?

- There are effective planning and selection of CP patients in cooperation with University Clinics.
- Close professional contacts with technical orthopedists, neurologist, ophthalmologist, orthopaedic surgeon, psychiatrist.
- Experienced multi-professional team with few staff turnover and well educated young colleagues.
- There is availability of intensive therapy unit with anaesthesiologist on 24 hour duty.
- Close contacts with Vaivari Assistive Technology Centre.
- Close cooperation with NGO's for re-socialisation and recreation.

### B. WHAT ARE THE POINTS TO IMPROVE IN YOUR PROGRAMME?

- Reduction of spasticity with baclofen pump.
- Stomatology, hygienist cabinet for CP children.
- Robotic technology systems and fitness equipment.

### C. WHAT ACTION PLAN DO YOU INTEND TO IMPLEMENT IN ORDER TO IMPROVE YOUR PROGRAMME?

#### 1. *Extrinsic conditions that you wish to obtain*

- Extensions of the spasticity programme with baclofen pump implantation.
- Implementation of robotic technologies and extension of fitness equipment.
- Reduction of salivation using Botulinum toxin and a hygienist on regular basis.
- Newest Alternative communication aids for CP patients.
- Enlargement of the rehabilitation team by a recreational therapist.

#### 2. *Intrinsic improvement of the programme*

- Learning workshop about using specific assessment tools for all team members.
- Digital medical records.
- Regular training and education program of the staff.
- Prevention of Burn-out syndrome, regular staff supervisions.
- International cooperation and research work.

## VI. References

Please, list here all references cited in your document in the same format as in scientific journals (eg EJPRM). References can consist of Cochrane or National Guidelines, papers published in indexed journals, documents published on official websites.

For national documents, please give details about the source and write down an abstract in English.

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