Protocol design of PTT program in children with CP after SEMLS.

It is important to realize that a standard SEMLS patient does not exist. Depending on the different SEMLS surgery procedures and protocols it is not possible to describe one type of fixed treatment protocol or one type of patient. Therefore, it is important to consider the following factors:

1. Surgery: a different progression during PTT will be seen after SEMLS depending on whether one or both legs are operated and whether two or three levels of surgery (ankle, knee, and hip) was needed.
2. GMFCS level: children with CP GMFCS I and II show more selectivity and are able to perform the exercises more easily compared to children with GMFCS III.
3. Other factors: Cognitive level, the ability to use two hands and the support of the child's system (parents, teachers etc.) have a crucial influence on the performance and progress of the treatment.

During the period of immobilization, exercises and specific instructions are given according to the protocols of the orthopedic surgeon. In order to make adequate use of the new alignment and gait opportunities (possibilities), co-interventions such as orthosis, plaster and devices are needed in the post-surgery intervention plan.[1-3] Adequate planning of the co-interventions is essential in order to start PPT. This care preferably will be organized in a specialized multidisciplinary team that will be coordinated by the rehabilitation physician. Four to six weeks after surgery, X-rays will be taken and the orthopedic surgeon will decide if mobilization can be started with full body weight, using temporarily ankle and knee immobilizers to guarantee the safety of the child during standing. When 100% weight bearing is not allowed the child need to stand with support of a stander and walk with crutches if possible combined with the non-weight-bearing exercises and instructions.

The care for these patients needs to be individually tailored and patients and their parents should be accompanied by the expert team both pre- and postoperatively.

We present a framework of important elements of the PTT after SEMLS at the point that the child has permission from the orthopedic surgeon to bear full weight with ankle and knee immobilizers, typically 4-6 weeks after surgery:

1. *Goal:*
   From completely inactive (bedridden) to fully active on all levels (depending on the rehabilitation goals) of ICF-CY in which pain and fatigue are crucial factors to be

considered during treatment, because the child did not bear weight on their legs for 6 weeks. With guidance from a physical therapist, the child learns to regain strength within the new ROM after SEMLS and the child needs to learn a new pattern for standing and walking activities in daily live.

2. *Frequency and duration 4-6 weeks post-operatively till 24 months*
   - 4 to 6 weeks post-surgery, depending on the consolidation of the bones, the intense 4 weeks of daily PTT starts till 8 to 10 weeks for 1.5-2 hours, combined with 1.5 to 2.5 hours independent performance of instructed exercises by child and parents.
   - From week 8 to 10 weeks till 6 months weeks; 3-5 times a week 1 hour a day PTT and 1-2 hours a home program
   - 6-12 months; 2-4 times a week 1 hour a day PTT and 0.5-1 hours a home program
   - 12-24 months; 1-2 times a week ½ -1 hour a day PTT

See table 1.

Table 1. SEMLS treatment schedule

Surgery	Post-surgery recovery time	Time line Start	End	Frequency Per week	Duration PTT	Duration independent exercises Institute	Duration independent Program at home
SEMLS	4-6 weeks	4-6 Weeks	8-10 weeks	Daily	1.5-2 h	1.5-2.5 h	
		8-10 weeks	6 months	3-5	1 h		1-2 h
		6 Weeks	12 months	2-4	1 h		0.5-1 h
		12 months	24 month	1-2	0.5-1		

Note: More or less PTT is possible depending on the policy of the orthopedic surgeon

3. *Intensity and method of treatment*

- *4 to 6 weeks post-surgery:* It is essential for the start of the PTT to manufacture optimal ankle and knee immobilizers. From day one the child will be placed in a standing position with the immobilizers to support standing and to guarantee the safety of the child. Within the treatment during the transition from standing to walking, it is important to align the orthoses with shoes.

From day one the child starts with strength training 3-4 times a week from unloaded to functional loaded exercises according to the method of progressive resistance exercise training using the repetition maximum method.[4] This means 1-3 sets of each exercise and within each set, muscle

fatigue is reached between 6-12 repetitions. Criteria for quality of moving are leading during muscle strength exercises to increase the load. The following muscle groups are trained specifically: hip extensors, hip abductors, knee extensors, abdominal muscles and when possible plantar flexors depending on the use of ankle foot orthoses (AFO's).

First, the aspect of the quality of movement while standing and walking is essential. The focus on the gait pattern is heel strike, extension of the knee and hip during midstance with a minimal pelvic drop and keep extend the knee and hip throughout the standing phase in order to facilitate knee flexion during swing phase. The child needs to adapt to the weight on their heels during standing and walking, which is a new condition, as before SEMLS, the child did not bear weight on their heels. Use of manual and verbal feedback [5], walking aids and technologies, such as body weight support treadmill training and body weight support over ground training (Zero-G), are beneficial in learning a new gait pattern.[6;7]

The child starts always in the walkway and weight supported treadmill training will be used along with crutches, tripods or a backward rollator. If possible, Zero-G training will be used. The bodyweight supported treadmill training will start daily when knee flexion reaches 80 degrees. The speed starts from 0.1 to 0.5 km/h, with 30-50% bodyweight support and 2-3 x 2 minutes walking. After 4 weeks the speeds vary from 0.5 to 1.5km/h, with 10-30% bodyweight support and 3 x 3-6 minutes walking. The amount of time the patient will use a walking device will depend on individually recover time.

When the SEMLS is performed on one leg and the child has an optimal hand function, crutches are used. When the SEMLS is performed on two legs and the child has an optimal hand function, tripods are used. When indicators are described of a restricted cognitive level are present, a limited use of two hands and the support of the child's system is confined, a backward rollator will be considered. The child leaves the rehabilitation center with the aid of a walking device. The decision of which walking aid to use will depends on the progress of the child.

It is important to keep the active and passive ROM obtained by SEMLS. During the immobilization period, knee immobilizers are worn and the knee flexion is limited. ROM exercises and variation of posture will be provided including; the hip flexors, hip adductors, knee flexors, knee-extensors and the m. gastrocnemius. Variation of posture will be offered during the day by having the child lying in prone, sitting with straight legs, standing in a stander, biking on a Motomed or a special hometrainer to optimize the active and passive ROM and will be used daily1-2 times for 10-30 minutes.

Balance training will be started in standing position with knee and ankle immobilizers. Exercises start with weight shifting from one leg to the other, balance while walking with

(minimal) walking aids and to training for falls. For children that have SEMLS performed on one leg, it is possible to stand without the knee immobilizers at the end of the first week or beginning of the second week of the PTT. For children that have SEMLS performed on two legs, it is possible to stand without the knee immobilizers in the end of the second week or beginning of the third week of the PTT. Practice based observation indicates that this has been the case for the vast majority of children.

From the beginning of the rehabilitation, a daily, individually structured home program will be made of the four elements described above, including variation of posture and exercises for: strength, gait, the active and passive ROM and balance. However, recovery time for the child is also an essential part. Activity of daily living (transfers in- and out of bed, dressing, toilet etcetera) are part of daily training, preferably during daily care using devices when necessary guided by an occupational therapist. A multidisciplinary approach is necessary to maintain the methods and the quality of exercise training to ensure the quality of the treatment.

After 4 weeks of training in a rehabilitation center, the treatment is transferred to a private practice where the patient was previously being treated, coached by the physical therapist of the rehab center. Focal points of treatment will be gait training, strength training, balance training, maintaining the active and passive ROM related to meaningful and functional activities. Outlining of the orthosis remains a point of attention.

- *2-6 months:* In this phase it is likely possible to work on the specific activities that are part of the child's request, because the cardiovascular and strength condition on body and functioning level is still insufficient. Functional (supported) gait training to learn a new walking pattern and preservation of the new active ROM is continued. Functional muscle strength training is intensified in load. Orthoses are used and the use of a walking aid is reduced depending on the abilities of the child. Based on our clinical experience we advise to use an assistive device until the patient is strong enough to overcome trunk sway (leaning to one side when lifting the opposite leg) or a minimal pelvic drop. Balance and gait training on the GRAIL (Gait Real-time Analysis Interactive Lab) is optional.

- *6 to 12 months:* The patient's needs are now prioritized, taking into account the post-surgery recovery. In the first half year, the focus was therefore more on function and activity level (ICF-CY) and from this period on the emphasis is more on participation level. The walking is optimized and functional muscle strength training is intensified in load with more complex exercises and combined with aerobic/anaerobic endurance training. The support during gait

training is further minimalized during daily activity, depending on the child's progress with the training. In this phase the initial request and goals of the child are more within reach and a high frequency and intensity of the PTT is required due to the need to improve muscle strength, as the condition of the body is still recovering from SEMLS. Balance and gait training on the GRAIL is optional.

- *12-24 months:* The emphasis is on fine-tuning of daily life activities and sports activities, which includes functional strength training combined with the emphasis on aerobic/anaerobic endurance training. The frequency of physical therapy is dependent on the goal of the patient in this phase. Children with GMFCS I and II walk without walking devices. Most children will go through the pubertal growth spurt with marked changes in height, weight and sometimes in body mass index [2] and therefore monitoring is important.

Evaluations by the rehabilitation center take place 25 weeks, 1 year, 2 and 5 years post-operatively as seen in the literature. [8;9] Twelve weeks post-operatively, the child is seen by the orthopedic surgeon for monitoring the progression of the consolidation of the child's bones.

Suggestions for measuring instruments for evaluation

Pre- and post-measurements are depending on the goals of the child and the parents, for the SEMLS and the PTT. We advise the following measurements on the different ICF-CY levels:[10-21]

- Function level:
  - physical examination of lower extremity (mobility, selectivity, strength, spasticity)
  - 3 D Gait analysis (step-length, walking speed, kinematics lower limbs)
  - 10 meter timed walking test
  - 1 minute walking test
- Activity and participation level:
  - Canadian Occupational Performance Measure
  - The Goal Attainment Scaling
  - Gross Motor Function Measure (Domain D and E)
  - Functional Mobility Scale
  - Mobility questionnaire
  - Quality of life Questionnaire to be determined

Reference List

(1) Khan MA. Outcome of single-event multilevel surgery in untreated cerebral palsy in a developing country. *J Bone Jt Surg Ser B* [serial online] 2007;89:1088-1091.

(2) Thomason P, Baker R, Dodd K et al. Single-event multilevel surgery in children with spastic diplegia: a pilot randomized controlled trial. *The Journal of bone and joint surgery American volume* [serial online] 2011;93:451-460 Available from: Hugh Williamson Gait Laboratory, Royal Children's Hospital, Melbourne, 50 Flemington Road, Parkville, Victoria 3052, Australia. pam.thomason@rch.org.au.

(3) Thomason P, Graham HK. Rehabilitation of children with cerebral palsy after single-event multilvel surgery. In: Iansek R, Morris ME, eds. *Rehabilitation in movement disorders*. Cambridge Univeristy; 2013;203-216.

(4) Scholtes VA, Dallmeijer AJ, Rameckers EA et al. Lower limb strength training in children with cerebral palsy--a randomized controlled trial protocol for functional strength training based on progressive resistance exercise principles. *BMC Pediatr* 2008;8:41.

(5) Sidaway B, Bates J, Occhiogrosso B, Schlagenhaufer J, Wilkes D. Interaction of feedback frequency and task difficulty in children's motor skill learning. *Phys Ther* 2012;92:948-957.

(6) Grecco LA, de Freitas TB, Satie J, Bagne E, Oliveira CS, de Souza DR. Treadmill training following orthopedic surgery in lower limbs of children with cerebral palsy. *Pediatric Physical Therapy* 193;25:187-192.

(7) Smania N, Bonetti P, Gandolfi M et al. Improved gait after repetitive locomotor training in children with cerebral palsy. *Am J Phys Med Rehabil* 2011;90:137-149.

(8) Harvey A, Rosenbaum P, Hanna S, Yousefi-Nooraie R, Graham H. Longitudinal changes in mobility following single-event multilevel surgery in ambulatory children with cerebral palsy. *Journal of Rehabilitation Medicine (Stiftelsen Rehabiliteringsinformation)* 2012;44:137-143.

(9) Thomason P, Selber P, Graham HK. Single Event Multilevel Surgery in children with bilateral spastic cerebral palsy: A 5 year prospective cohort study. *Gait & posture* 2013;37:23-28.

(10) Oeffinger D, Bagley A, Rogers S et al. Outcome tools used for ambulatory children with cerebral palsy: responsiveness and minimum clinically important differences. *Dev Med Child Neurol* 2008;50:918-925.

(11) Booth ATC, Buizer AI, Meyns P, Oude Lansink ILB, Steenbrink F, van der Krogt MM. The efficacy of functional gait training in children and young adults with cerebral palsy: a systematic review and meta-analysis. *Dev Med Child Neurol* 2018.

(12) Himuro N, Abe H, Nishibu H, Seino T, Mori M. Easy-to-use clinical measures of walking ability in children and adolescents with cerebral palsy: a systematic review. *Disabil Rehabil* 2017;39:957-968.

(13) Verkerk GJ, Wolf MJ, Louwers AM, Meester-Delver A, Nollet F. The reproducibility and validity of the Canadian Occupational Performance Measure in parents of children with disabilities. *Clin Rehabil* 2006;20:980-988.

(14) Steenbeek D, Gorter JW, Ketelaar M, Galama K, Lindeman E. Responsiveness of Goal Attainment Scaling in comparison to two standardized measures in outcome evaluation of children with cerebral palsy. *Clin Rehabil* 2011;25:1128-1139.

(15) Steenbeek D, Ketelaar M, Lindeman E, Galama K, Gorter JW. Interrater reliability of goal attainment scaling in rehabilitation of children with cerebral palsy. *Arch Phys Med Rehabil* 2010;91:429-435.

(16) Ko J, Kim M. Reliability and responsiveness of the gross motor function measure-88 in children with cerebral palsy. *Phys Ther* 2013;93:393-400.

(17) Harvey AR, Morris ME, Graham HK, Wolfe R, Baker R. Reliability of the functional mobility scale for children with cerebral palsy. *Phys Occup Ther Pediatr* 2010;30:139-149.

(18) Harvey A, Graham HK, Morris ME, Baker R, Wolfe R. The Functional Mobility Scale: ability to detect change following single event multilevel surgery. *Dev Med Child Neurol* 2007;49:603-607.

(19) van Ravesteyn NT, Dallmeijer AJ, Scholtes VA, Roorda LD, Becher JG. Measuring mobility limitations in children with cerebral palsy: interrater and intrarater reliability of a mobility questionnaire (MobQues). *Dev Med Child Neurol* 2010;52:194-199.

(20) van Ravesteyn NT, Scholtes VA, Becher JG, Roorda LD, Verschuren O, Dallmeijer AJ. Measuring mobility limitations in children with cerebral palsy: content and construct validity of a mobility questionnaire (MobQues). *Dev Med Child Neurol* 2010;52:e229-e235.

(21) Lundkvist JA, Jarnlo GB, Gummesson C, Nordmark E. Longitudinal construct validity of the GMFM-88 total score and goal total score and the GMFM-66 score in a 5-year follow-up study. *Phys Ther* 2009;89:342-350.