

**POSTER TITLE:** Family centered early motor intervention in children with severe congenital heart disease

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## ABSTRACT

### Background

Infants with severe congenital heart disease are a group of children at risk for neurodevelopmental impairments. Survival rates have increased dramatically due to improvement in neonatal, perioperative and surgical management. Motor development is the first domain to show a delay during the first year of life with a frequency of 30-60%. Early motor difficulties may contribute to parental concerns, stress and difficulties in early child-parent attachment. In addition, they can constitute early markers for later developmental difficulties in motor but also other developmental domains. There is evidence from other populations at risk that early family centered therapy can promote developmental progress.

### Aims and Objectives

This project aims to identify needs and concerns of parents of children with severe congenital heart disease on how to best promote their infants' motor development in the first year of life. In a second step, we aim to investigate a family centered early motor intervention for infants after open heart surgery, based on the parental needs' analysis. The intervention will focus on the active involvement of parents to promote their infant's motor development and determine if this will have an influence on the infant's motor development and the parental quality of life.

### Methods

- a. Parental Interviews: Identifying parents' needs that are based on their own experiences in relation to their child's motor development in the first year of life.
- b. Family centred motor intervention: Providing a pilot early motor intervention for infants after open heart surgery (EMI Heart) developed based on parental needs' analysis and evidenced based elements of early intervention.

### Our Assumption

We assume that involving parents as early as possible into the care and developmental support for their infant will promote early child-parent attachment, infants' motor development and increase family's quality of life.