

## **Becoming an adult: A qualitative study of experiences of young people suffering from neuromuscular disease during transition into adulthood and their families**

### **Abstract**

This study will explore experiences of young persons affected by neuromuscular disease and their families during transition into adulthood. Becoming an adult is considered to be a normal developmental stage within the life cycle. However, a chronic childhood condition can disrupt that transition and may have impact on the young persons' and their families' lives.

Therefore, this study aims to understand experiences of families suffering from neuromuscular disease during transition of the affected young person into adulthood and to identify major challenges and strategies by which individuals and families successfully adapt to new situations. The following overarching research question is the focus for the investigation: Where a young person is affected by neuromuscular disease, what are theirs and their family member's experiences of their transition into adulthood?

The study design is a constructivist approach to Grounded Theory. Data are collected from single interviews with young people affected by neuromuscular disease and their families. Data collection takes place in Switzerland. Inclusion criteria for the young person affected by neuromuscular disease are age range between 14 to 25 years, resident in Switzerland, first symptom onset of the genetic neuromuscular disease in childhood and moderate to severe physical impairment. Moreover, parents, younger and older siblings and other next of kin of such a young person are asked to participate. The sample size is estimated to be 40 participants of approximately 8 to 15 families. Interviews will be recorded and transcribed verbally. Collected data will be analysed using coding, memo writing and theoretical sampling aiming at data based theory development. The intent of this study is to move beyond description and to generate a general interpretation of the transition from childhood into adulthood which young people and their families experience.