

**UCD792034-1: The Use of Online Screeners to Identify
Developmental Delays & Behavioral Challenges
in Young Boys with Duchenne Muscular Dystrophy (DMD)**

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This dissertation research study aims to determine if online developmental and behavioral screening tools could be used to detect possible developmental delays and behavioral challenges in young boys (under 84 months of age) with Duchenne Muscular Dystrophy (DMD). Previous studies have demonstrated that males with DMD have higher percentages of language, cognitive, social-emotional, and behavioral challenges than males in the overall population (Cyrulnik et al., 2008; Cyrulnik et al., 2007; Davies, 1997; Polakoff et al., 1998; Wu et al., 2005). A recent study by Connolly and colleagues (2013, 2014) found that these delays are evident even in very young boys with DMD, when assessed with a norm-referenced comprehensive behavioral assessment of development (Bayley, 2005). The current study aims to determine if a higher percentage of young boys with DMD score in the concern range on developmental and behavioral screeners than an age-matched control group of unaffected boys. The study results may indicate that using developmental and behavioral screeners with young boys with DMD at time of diagnosis could identify those that are “at risk” for delays and behavioral challenges and therefore might benefit from a comprehensive developmental assessment and early intervention services.

Considering that previous studies have demonstrated that young boys with DMD are at a higher risk for co-occurring developmental delays and behavioral challenges, it is important to identify unmet need for early intervention in these areas. Studies to date have only looked at unmet need for additional developmental and behavioral treatment in older school-age boys with DMD (Firth et al., 1983; Darke et al., 2006), and both of these studies were conducted in the U.K. The current study also aims to identify areas of unmet need for early intervention in young boys with DMD in the United States, in an attempt to identify services that could benefit these boys even before they attend school.

This study will be conducted primarily through completion of online parental questionnaires by families in the United States. In order to achieve sufficient statistical power, 125 parents of boys diagnosed with DMD under 84 months of age are needed for this study. Each parent-child dyad for the group of children with DMD must meet the following inclusion criteria: 1) parents must report that their child received a diagnosis of DMD from a health care professional; 2) the child must be male; 3) the boy with DMD must be under 84 months of age at time of enrollment in the study; 4) parents must be able to read and write English; and 5) parents must have access to the internet in order to complete study questionnaires.

A control group comprised of 125 parents of boys without a diagnosis of DMD will also be recruited. In an attempt to match the control group to the DMD group in as many ways as possible, parents of boys with DMD will be encouraged to invite a parent of a male peer of similar chronological age who is not diagnosed with DMD to complete the online questionnaires on their own child's development and behavior (Seltzer et al., 2004; Thomas et al., 2009). Each parent-child dyad for the non-DMD control group must meet the following inclusion criteria: 1) parents must report that their child has not received a diagnosis of DMD from a health care professional; 2) the child must be male; 3) the child must be under 84 months of age; 4) parents must be able to read and write English; and 5) parents must have access to the internet in order to complete study questionnaires.

*Thank you for your interest in this study. Please contact Amy Wagner at alwagner@ucdavis.edu or at 530-564-8310 if you have any questions.

*Here is the link to more information about the study and the link to enroll in this online study:
<http://www.ucdmc.ucdavis.edu/pmr/research/DMD-study.html>