Wellbeing in Mothers Caring for a Child with Duchenne or Becker Muscular Dystrophy

Parent Project Muscular Dystrophy and Cincinnati Children’s Hospital Medical Center are conducting a research study to learn more about the experiences of mothers caring for a child with Duchenne or Becker muscular dystrophy (DBMD).

Study goal
This study will help us to determine how the experiences and wellbeing of mothers caring for a child with DBMD change over time. The overall goal of the study is to obtain information to support the development of interventions for mothers that aim to improve their wellbeing.

Who can participate?
This study is open to English-speaking females, 18 years of age or older, who are biological mothers of one or more children with DBMD. The child with DBMD can be any age. All participants must currently be residing in the U.S. and be willing to participate in this study for 5 years.

What is involved in participating in the study?
Participation involves agreeing to be a part of this study and answering the surveys that will be sent to you either on-line or in the mail. After the initial survey has been completed, shorter follow-up surveys will be sent approximately every 6-12 months. You will be a part of this study for approximately 5 years unless you choose to withdraw.

What are the risks of the study?
The potential risks for participating in this study are minimal, but may involve becoming emotionally upset because of the questions asked in the survey. For that reason, participants will be provided with the contact information for a genetic counselor and support person from Parent Project Muscular Dystrophy.

If you want to sign up for the study or get more information, contact study investigator Holly Peay at holly@parentprojectmd.org or 443-791-5927.