

1p36 Deletion Syndrome Study Being Conducted at the 1p36 Deletion Support & Awareness Group 2014 Conference

Study about the Speech Skills and Heart Function of Individuals with 1p36 Deletion Syndrome

Study Details:

You are invited to participate in a research study called, "Investigation of Cardiomyopathy and Speech Delay in Individuals with 1p36 Deletion Syndrome. This study will be conducted at the 2014 1p36 Deletion Support & Awareness Group 2014 Conference at the Great Wolf Lodge in Mason, OH. We hope to get more information on speech delays and heart problems that individuals with 1p36 Deletion Syndrome may have.

Information from this study will be used to learn more about these features in association with the deletion syndrome, and may help change health care and management for these patients. This study will be done through the Division of Human Genetics at CCHMC and also with the Heart Institute at CCHMC and the Division of Speech-Language Pathology at CCHMC. This study is completely voluntary and you are free to decide not to participate, or to decide to participate in some, but not all of the study procedures. **Please contact Cassie Bac (contact information listed below) if you are interested in participating in this research study.**

What will happen during this research study:

This study will take place at the 1p36 Deletion Support & Awareness Group national conference on July 17-20th, 2014 at the Great Wolf Lodge in Mason, OH. These are the things that will happen to you while in the study:

- Speech-language skills and feeding skills will be assessed by a licensed speech language pathologist. These evaluations may include testing of speech-sound production, oral motor skills, hearing, feeding skills, and others. This may take about 1 hour to complete.
- The cardiac evaluation will include a routine echocardiogram (Echo) and electrocardiograph (ECG). This may take about 1 hour to complete.
- Collection of medical records. If there are medical records at other hospitals or doctor's offices, then you may be asked to sign a release of medical information so that the principal investigator may obtain copies of those records.

Contact us if you are interested in participating in this research study:

The researchers conducting this study are Cassie Bac, BS Genetic Counseling Student, and Robert Hopkin, MD. If you have any questions or are interested in participating in this study, please contact Cassie Bac by phone at (408) 621-1471, or by email at cassandra.bac@cchmc.org

Thank you for your time and consideration. We look forward to hearing from you!