



### **Purpose of the Study**

We are interested in creating cell culture models for CHARGE syndrome.

### **Participation Requests**

1. An adult or child of any developmental age who has clinical features of CHARGE Syndrome.
2. Collection of a blood sample.
3. Completion of clinical questionnaire and consent form.

### **Nature of Participation**

We will collect blood samples from individuals with clinical features of CHARGE Syndrome. Blood samples will be used to generate a population of cells known as induced pluripotent stem cells (iPSCs). iPSCs can be turned into other types of cells relevant to CHARGE to better understand the developmental processes that lead to clinical features. DNA may also be extracted from blood samples for sequencing studies to identify changes that may be associated with CHARGE. Information provided in the clinical questionnaire contributes to a CHARGE Syndrome cohort database to explore the natural history of CHARGE Syndrome.

### **Time Involved**

The requirements to participate in this genetic study can be completed in one or two sessions at our booth during the conference. In total, we request approximately 45 minutes of your time. Each participant will be asked to review and sign a consent form (~15 minutes), donate a blood sample (~15 minutes), and complete a clinical history questionnaire (~15 minutes, one questionnaire per family). A trained phlebotomist will be on-site for blood collections.

### **Contact Information**

If you have any questions regarding this study, please visit our booth during the conference or contact Ms. Amanda Moccia ([moccia@med.umich.edu](mailto:moccia@med.umich.edu)) or Dr. Donna Martin ([donnamm@med.umich.edu](mailto:donnamm@med.umich.edu)).