

NATURAL HISTORY STUDY OF CONGENITAL EPIGENETIC SYNDROMES

The Epigenetic Syndromes Clinic Team at Cincinnati Children's Hospital is conducting research on congenital epigenetic syndromes such as **Rubinstein-Taybi Syndrome, Menke-Hennekam Syndrome, Kabuki Syndrome**, and others with a goal of improving clinical care, developing objective outcome measures, and expanding treatment options. Therefore, we are actively enrolling participants of **all ages**. Through our collection of medical and family history, behavioral data, and biological samples, we aim to gain more knowledge about the natural course and molecular mechanisms of these disorders.

To participate in the study:

1. Email epigenetics@cchmc.org and express interest
2. Schedule a phone call to talk about the study with our study coordinator (**approximately 25 minutes**)
3. Fill out the behavior and medical and family history surveys that will be sent to your email (**approximately 1-1.5 hours**)

Total time to participate: **Approximately 2 hours**

You do not have to be a patient of Cincinnati Children's Hospital Medical Center or resident of Cincinnati to participate in this study.

As mentioned, we are also studying the molecular mechanisms of epigenetic syndromes through sample collection (e.g., blood, urine, spit). We store these samples in our Biobank at CCHMC for future research. Sample collection is optional and mostly geared towards our local participants, but please let us know if you're also interested.

Please reach out to our study coordinator, Dima Qu'd, by email (epigenetics@cchmc.org) or phone (513-803-4471) for more information.