

Appendix B: Data Collection Tool

Interviewee & Patient Information:

Interview ID: _____

Name of Interviewee(s):

Name of Patient:

Patient Sex:

Relationship(s) to Patient:

Patient DOB:

Patient Ethnicity:

Source: ☐ Parent report ☐ MR

Data Collection:

☐ Clinical Diagnosis (made before a genetic diagnosis ☐ Yes/ ☐ No)

☐ ___/___ (mm/yyyy)

○ Type of specialist who made diagnosis: _____

Source:

☐ Parent report ☐ MR

☐ Genetic Diagnosis (made before a clinical diagnosis ☐ Yes/ ☐ No)

○ ___/___ (mm/yyyy)

○ Type of specialist who ordered genetic testing: _____

Source:

☐ Parent report ☐ MR

○ Type of genetic test:

☐ Targeted testing for SLC52A2

☐ Panel

☐ Whole Exome Sequencing

☐ Other: _____

Source:

☐ Parent report ☐ MR

[illegible]

- Previous Incorrect/Suspected Diagnoses, Age & Who made the diagnosis:

Source:

☐ Parent report ☐ MR

- Audiology Data

- ☐ Age of diagnosis of Hearing Loss: _____
- ☐ Hearing aids: ☐ Yes / ☐ No
- ☐ Cochlear Implants: ☐ Yes / ☐ No
- ☐ How well does the patient communicate: _____
- ☐ Hearing with devices: _____
- ☐ How does your child communicate?
 - ☐ Speech ☐ Sign Language ☐ Tactile signs
 - ☐ Communication board ☐ Gesturing

Source:

☐ Parent report ☐ MR

- Future research:

Contact for future research? ☐

- Comments/Feedback:

- Medical Records

- ☐ Dr. Keith Massey

- ☐ CCHMC only

- ☐ No permission to review Medical Records

- Mailing Address of Interviewee (☐ NA)
