What is CHARGE Syndrome?

- A genetic condition caused by a mutation (i.e. change) in the gene CHD7.
- Occurs in approximately 1/10,000 births.
- Leading cause of deaf-blindness in the United States.
- Difficulty in one or more of the following areas:
  - Senses of hearing, vision, touch, taste, smell, pain, pressure
  - Motor skills and balance
  - Speech and language, learning
  - Feeding and swallowing, breathing
  - Behavior

What areas of communication are affected by CHARGE?

- Speech—how children produce sounds in their language
  - Children may have difficulty producing clear speech sounds due to differences in how the parts of their mouth and face are formed.
- Pragmatics—how children communicate in a socially appropriate manner
  - Behaviors such as facial expressions, body language, turn taking, and initiating conversations may be affected.
- Expressive language—what children “say”
  - Smaller vocabularies and difficulty forming sentences with the correct grammar (using verb endings such as past tense –ed).
- Receptive language—what children understand
  - Struggles with understanding concepts or following directions.

Consequences of Communication Problems

- Needs and wants (e.g. preference for a certain object) may not be met.
- Limited ability to interact with family and peers: social isolation.
- Inappropriate behaviors.
Role of the Speech-Language Pathologist (SLP)

- Identify how the child with CHARGE communicates
- Define demands of the child’s environment
- Specify most effective mode of communication
- Work with other professionals on the child’s team (e.g. physical therapist, occupational therapist, audiologist, educator of the deaf, teacher of the visually impaired, and special education teacher)
- Educate family and team members about ways to communicate with the child

Communication Strategies

- Give child more time to process information
- Repeat information
- Provide short, simple, clear directions
- Be flexible in using multiple modes of communication
- Maintain interaction at an appropriate eye level
- Touch cues to start/stop conversation (e.g. tap on the shoulder)
- Alert child to your presence

Classroom Modifications

- Set up face to face activities
- Assign different classroom staff to different areas of the room to provide a variety communication partners
- Provide consistent schedules and routines
- Label items in the classroom (Braille or large print as needed)
- Consult with the vision specialist and adapt materials as needed (e.g. make a prop box with objects to go with a story)

For more information about CHARGE Syndrome please visit:
CHARGE Foundation:  http://chargesyndrome.org/index.asp
National Center on Deaf-Blindness: https://nationaldb.org