Understanding Sensory Complexities in Infants & Toddlers with CHARGE Syndrome

Susanne Morgan Morrow, MA, CI, CT
New York DeafBlind Collaborative – Project Director

What is CHARGE Syndrome?

- A rare genetic syndrome
- Mutation of the CHD7 gene
- 1:10,000-1:15,000 live births
- Often born with life-threatening birth defects
- Often far surpass their medical, physical, educational, and social expectations

CHARGE Syndrome is the leading cause of deafblindness in congenitally DeafBlind children

Understanding CHARGE Syndrome

Major Characteristics

Coloboma of the eye

Heart defects

Atresia of the choanae

Restriction of growth & development

Genito-Urinary Defects

Ear abnormalities & deafness

Understanding CHARGE Syndrome

Additional Characteristics

Cranial nerve damage, craniofacial differences (facial palsy), cleft lip/palate

Hearing loss, hypotonia

Atresia of the esophagus, anxiety, apnea (sleep)

Renal issues

Gastrointestinal issues, g-tube feeding

Endocrine system

Understanding CHARGE Syndrome

- 30-50% have typical intelligence
- Intelligence of children with CHARGE is often underestimated because of combined hearing, vision and balance issues.
- Testing, therapies and educational intervention MUST consider hearing, vision and balance status.

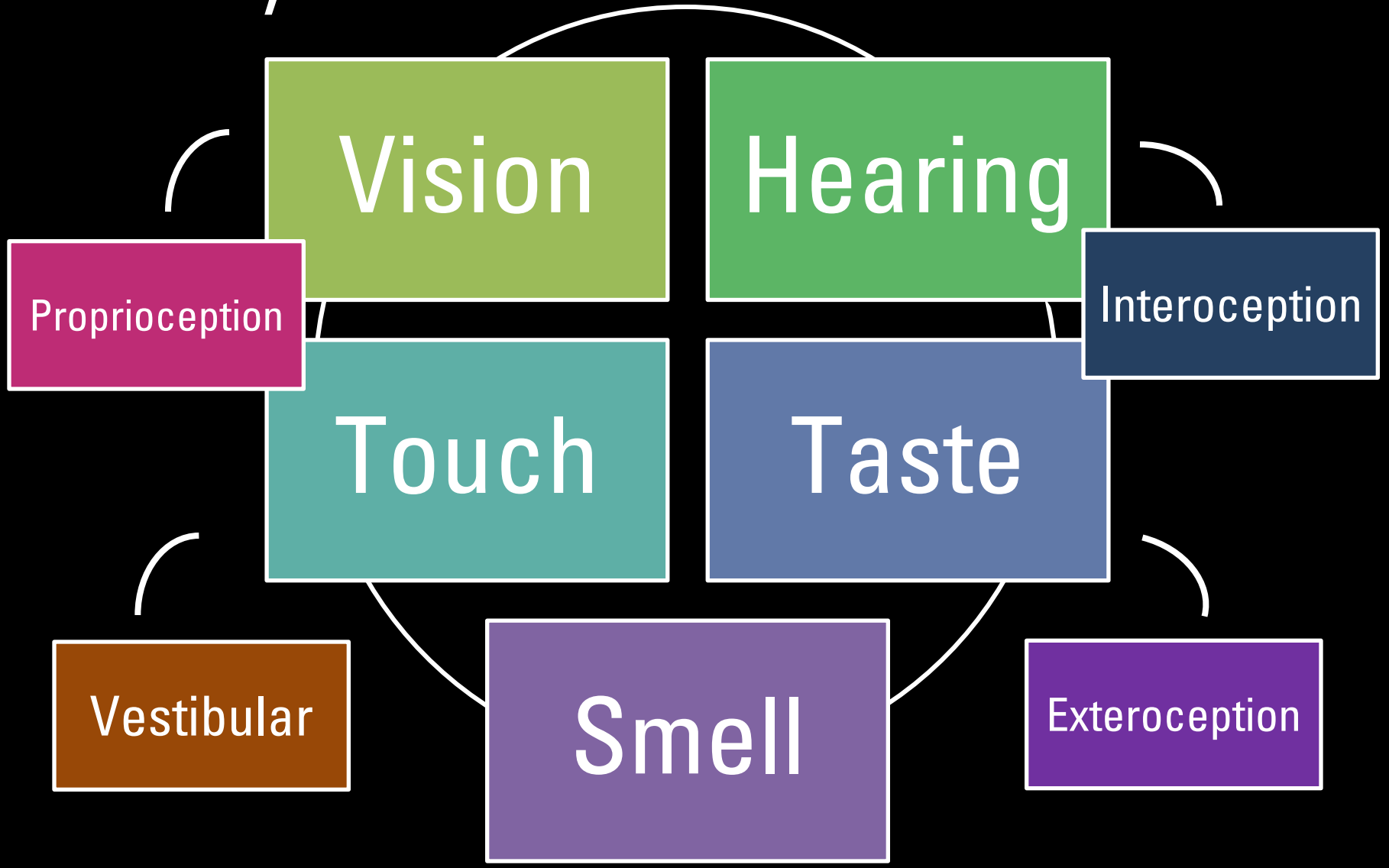
WHY I WALK AND ROLL FOR CHARGE

CHARGE SYNDROME FOUNDATION

7th Annual WALK & ROLL April 25, 2026

Understanding the Sensory System

Sensory Channels



Vestibular

The inner ear organs that maintain balance, posture, position & movement

- Peripheral vestibular system
- Central vestibular system

Peripheral Vestibular System

- Vestibular end organs
  - Three semicircular canals (detecting angular acceleration)
  - Two otolith organs (utricle and saccule, detecting linear acceleration and gravity)
- Vestibular portion of cranial nerve VIII, which transmits signals to the brainstem

Central Vestibular System

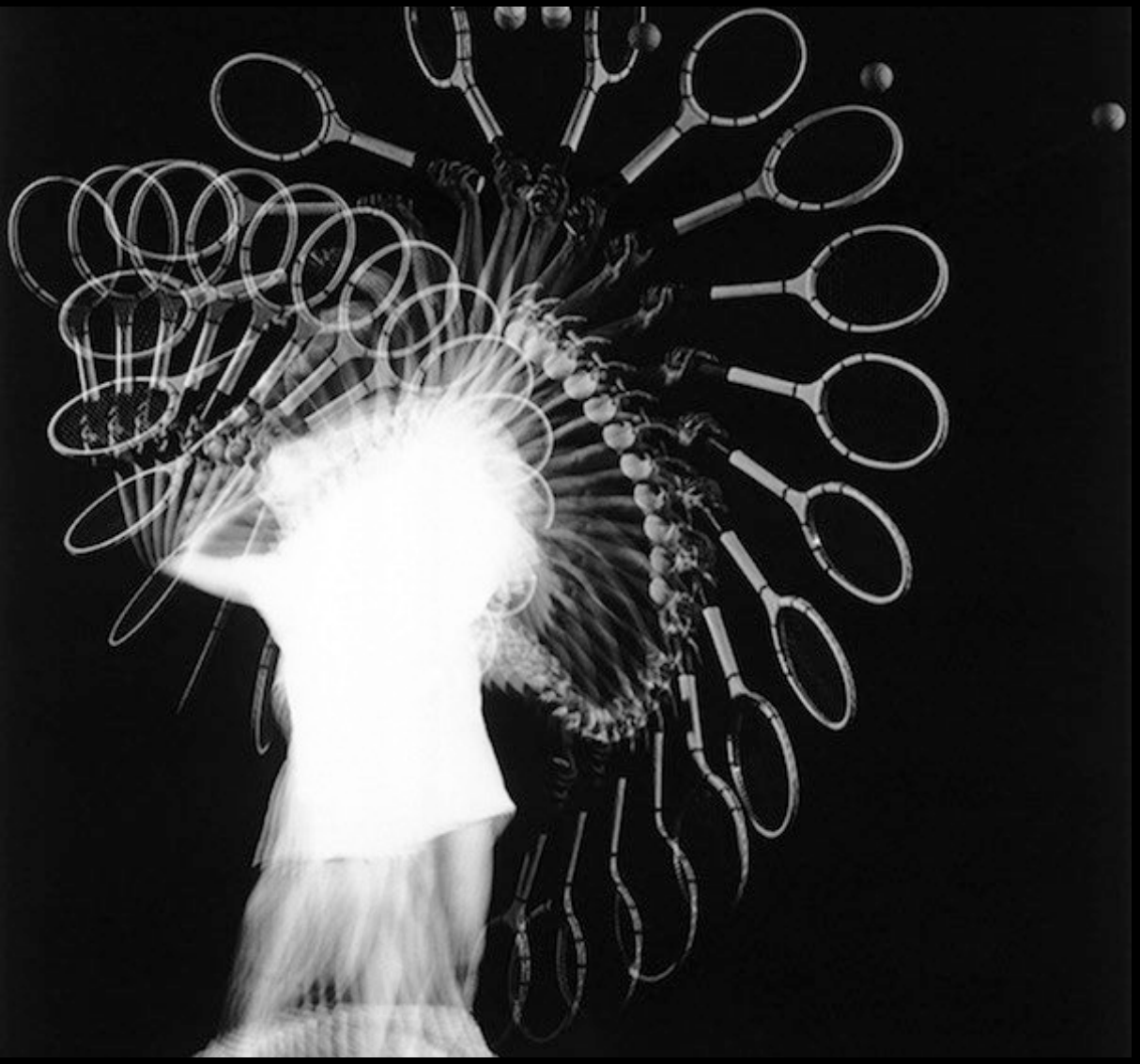
- Vestibular nuclei (lateral, medial, superior, inferior) at the pontomedullary junction
- Vestibulocerebellum (flocculonodular lobe and vermis)
- Vestibulo-ocular pathways (modulating gaze stability via the vestibulo-ocular reflex)
- Vestibulospinal pathways (contributing to postural control)
- Vestibular areas in the cortex (parietal-insular vestibular cortex, thalamus), supporting spatial orientation, motion perception, and multisensory integration
- Vestibulo-autonomic pathways (influencing autonomic responses and emotional regulation)

https://www.medbridge.com/blog/central-vs-peripheral-vestibular-dysfunction

Interoception

Your brain's representation of sensations from inside your own body, one's internal systems & organs

Proprioception



The sense of self-movement, force, and body position, also referred to as kinesthesia

Knowing where we are in space, automated movements bypassing the conscious mind

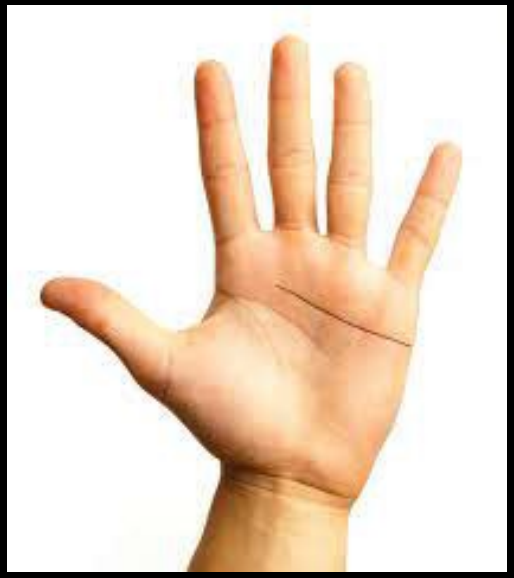
Exteroception

Sensitivity to stimuli that are outside the body from specialized sensory cells called exteroceptors to objects & occurrences in the external environment.

- Sights
- Sounds
- Smells
- Tastes
- Tangible objects

There are three places on the body that we do not grow hair.

What are they? Why is this important?



Why do kids bring things to their mouths?

- Information-seeking behavior
- Vibro-tactile input
- Sensory-soothing behavior

Why do kids take their shoes off?

- Feeling grounded (proprioception)
- Information-seeking behavior
- Tactile sensitivity/ input
- Sensory-soothing behavior

Why do we need to be mindful of the use of children's hands?

- Information-seeking
  - Things
  - People
  - Communication
  - Orientation

- Equate hand use to the mouth for spoken language or the eyes to seek out information

Early touch in the life of an infant is critical

Touch for infants & toddlers with CHARGE can have significant negative correlations

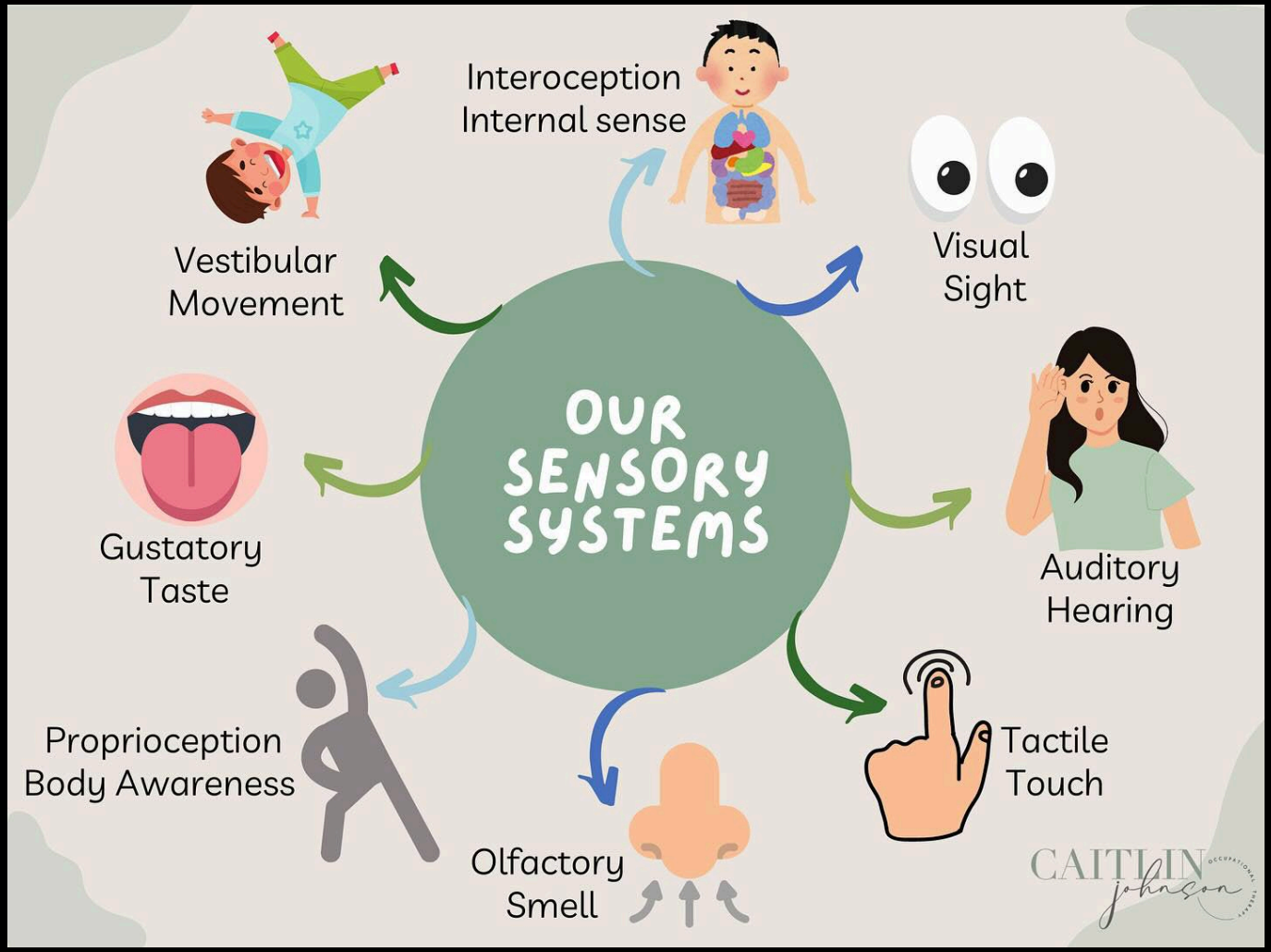
- Touch aversiveness
- Tactile defensiveness

California Deafblind Services – Belote, Brown & Maier

Studies show significant and longstanding impact on the global development in children when there is the absence of touch in infancy or the presence of negative touch

Understanding Sensory Complexities in Infants & Toddlers with CHARGE Syndrome

A holistic approach



Caitlin Johnson

Hearing Loss

- Variable – from mild to profound
- Possible hearing aids, bone conduction aids, cochlear implants

Vision Loss

- Optic Nerve Colobomas - depending on location
- May have upper field loss & acuity loss
- Iris Colobomas – may result in sensitivity to light, usually impacted in one eye causing monocular vision, impacting depth perception

Vestibular Issues

- Balance, Motor coordination
- Sense of self in space

Tactile

- Unusual sensitivity to touch
- Inefficiency in processing pain

Lack of Sensory Integration

- Delay in processing
- Does not mean doesn’t comprehend

Adult-Only CHARGE Syndrome Zoom Social

New York CHARGE Syndrome Families 2025

NEW YORK DEAFBLIND COLLABORATIVE
www.nydeafblind.org

NYDBC Website
www.nydeafblind.org

NYDBC Email
nydeafblind@gmail.com

Project Director
Susanne Morgan Morrow –
susanne.morrow@qc.cuny.edu

Family Engagement & Outreach Coordinators
Suzanne Chen – Lead
suzanne.chen@qc.cuny.edu

Nanci Bentley – Western New York
nanci.bentley@qc.cuny.edu

Alexandra Fiallos – Spanish
alexandra.fiallos@qc.cuny.edu

Project Assistant
Lisa Tsang – lisa.tsang@qc.cuny.edu

The contents of this presentation were developed under a grant from the U.S. Department of Education (H326T130007). However, this content does not necessarily represent the policy of Queen's College nor the US Department of Education and you should not assume endorsement by the Federal Government. Project Officer, Carlene Reid

IDEAs that Work
Office of Special Education Programs
U.S. Department of Education

Thank you!

susanne.morrow@qc.cuny.edu
www.nydeafblind.org