CEREBRAL/CORTICAL VISUAL IMPAIRMENT IN DOWN SYNDROME

Translating Current Research into Clinical Practice and Creating Momentum Towards Broader Awareness

ANNUAL symposium

DSMIG-USA®
Down Syndrome Medical Interest Group

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July 23-25
Orlando, Florida

FACULTY & TALK COORDINATOR

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Co-chair DSMIG DS+CVI Workgroup
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Parent of teen with DS+CVI

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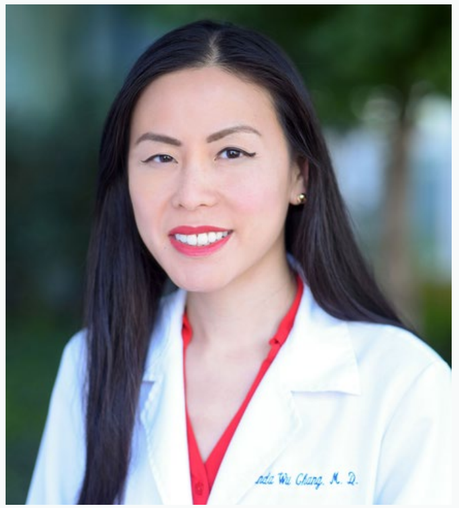

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Parent of a young adult with DS

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Chelsea Werner: @showtimewerner

The outlook for individuals with DS today is better than ever

- Robust, energetic, collaborative DS community
- Advances in research, health care, and education
- Improved life expectancy, quality of life, opportunities

THE DOWN SYNDROME PHENOTYPE

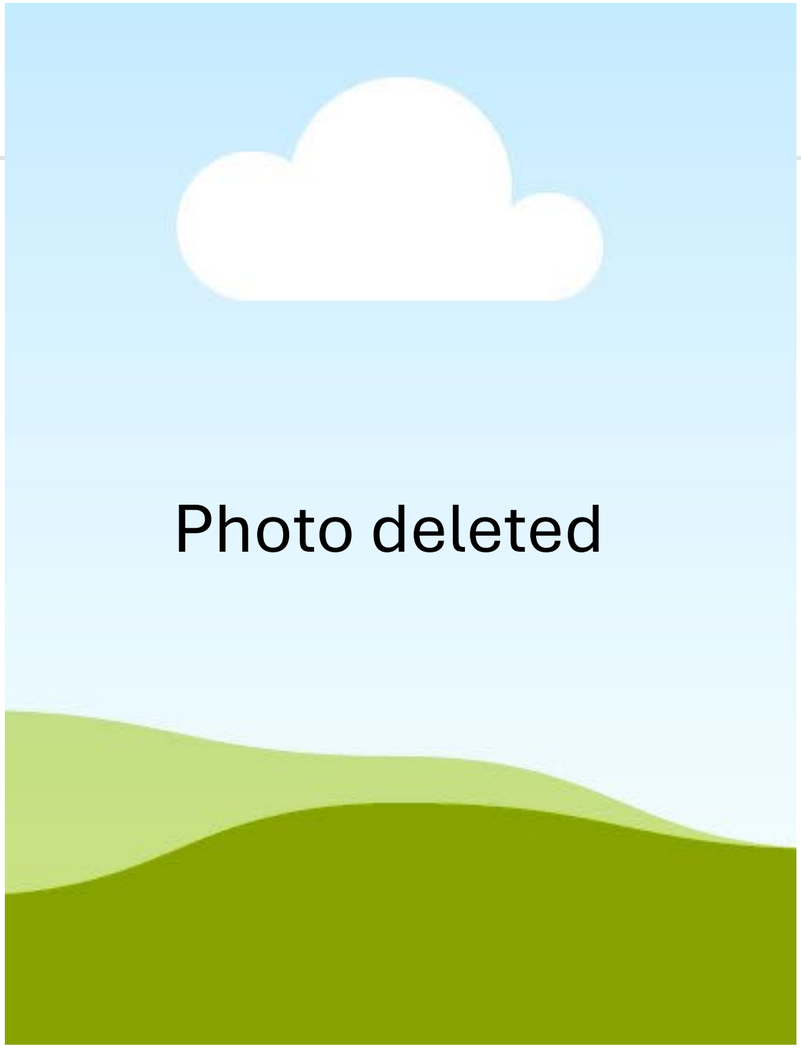
- Medical profile
- Learning profile
- Behavioral Profile
- Cognitive Profile
- Developmental Profile

CVI IN DOWN SYNDROME

Case series describing 3 teens with DS+CVI:

- Eye conditions common in DS
- Delayed developmental milestones
- Language challenges
- Behaviors
- Late diagnoses of CVI (teen years)
- All three responding to CVI accommodations/ deafblind techniques
- Delays and behaviors in DS may reflect inconsistent visual and auditory access, not reduced capacity.

Boatwright E, Banihani R, Willems I, Lehman K, Mazel E, Mark H, Wong M, Vietzman S, Chandna A and Heidary G (2025) Cerebral/Cortical visual impairment (CVI) in Down syndrome: a case series. Front. Hum. Neurosci. 19:1563420. doi: 10.3389/fnhum.2025.1563420



LEARNING OBJECTIVES

As a result of participation in this activity, members of the healthcare team will be able to:

1. **Describe** the characteristics of CVI.
2. **Understand** how CVI is diagnosed in Down syndrome.
3. **Summarize** research findings about CVI in Down syndrome.
4. **Recognize** features of functional deafblindness resulting from CVI and hearing impact in Down syndrome.
5. **Illustrate** what interventions are typically effective in supporting those with DS+CVI versus other diagnoses with potentially overlapping features.

[Recorded presentation - play here]

CEREBRAL/CORTICAL VISUAL IMPAIRMENT: AN OVERVIEW

Gena Heidary, MD, PhD

Director, Pediatric Neuro-ophthalmology Service

Director, Pediatric Ophthalmology Fellowship

Pediatric and Adult Strabismus

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DISCLOSURES

- No relevant financial disclosures
- Royalties: Springer

WHAT IS CEREBRAL/CORTICAL VISUAL IMPAIRMENT (CVI)?

- **DEFINITION**
  - CVI represents brain-based visual impairment characterized by afferent dysfunction, which exceeds but may be comorbid with ocular conditions
  - Although the injury which results in CVI occurs during visual development, often the condition is unrecognized until later.
  - CVI is distinct from other brain-based disorders of language, cognitive function, or social function.
- Retro-geniculate pathway injury, which may include
  - Optic radiations
  - Occipital cortex
  - Higher-order visual association centers
- The diagnosis is a clinical one and requires a multidisciplinary approach

Chang MY, Merabet LB, Trans-NIH CVI Working Group. Cerebral/cortical Visual Impairment (CVI) Working Definition: A Report from the National Institutes of Health (NIH) CVI Workshop. Ophthalmology 2024.

EPIDEMIOLOGY OF CVI

- Leading cause of significant visual impairment in children in developed countries
- UK population-based study of children with profound vision loss: 48% CVI
- Survey 2298 primary school children aged 5 to 11 years, 3.4% of the sample had CVI

Kong et al., JAAPOS 2012; Merabet et al, Sem in Pediatric Neuro, 2017; Williams et al., Dev Med Child Neurol 2021; 63: 683-689.

COMMON DIAGNOSES ASSOCIATED WITH CVI

- Perinatal hypoxia/ischemia
  - Term infant: there is injury to the cortical watershed areas: parieto-occipital infarction
  - Periventricular leukomalacia (hypoxic/ischemic)
  - Premature infant: there is injury to the subcortical visual pathways; this affects the optic radiations
- Down Syndrome
- Other Genetic Conditions which impact neurological function (e.g. CDKL5 disorder)
- Head injury/ trauma
- Hydrocephalus
- Infection (e.g. encephalitis, meningitis)
- CNS malformations
- Metabolic disorders
- Neurodegenerative disorders

COMORBIDITIES IN THE SETTING OF CVI

- Cognitive deficits/delay
- Seizures
- Motor deficits/cerebral palsy
  - Retrospective review 218 children from Boston Children's 28% had CP
  - Retrospective review 249 individuals Cincinnati Children's with CVI 60.3% had CP
- Other sensory deficits (e.g. hearing loss)

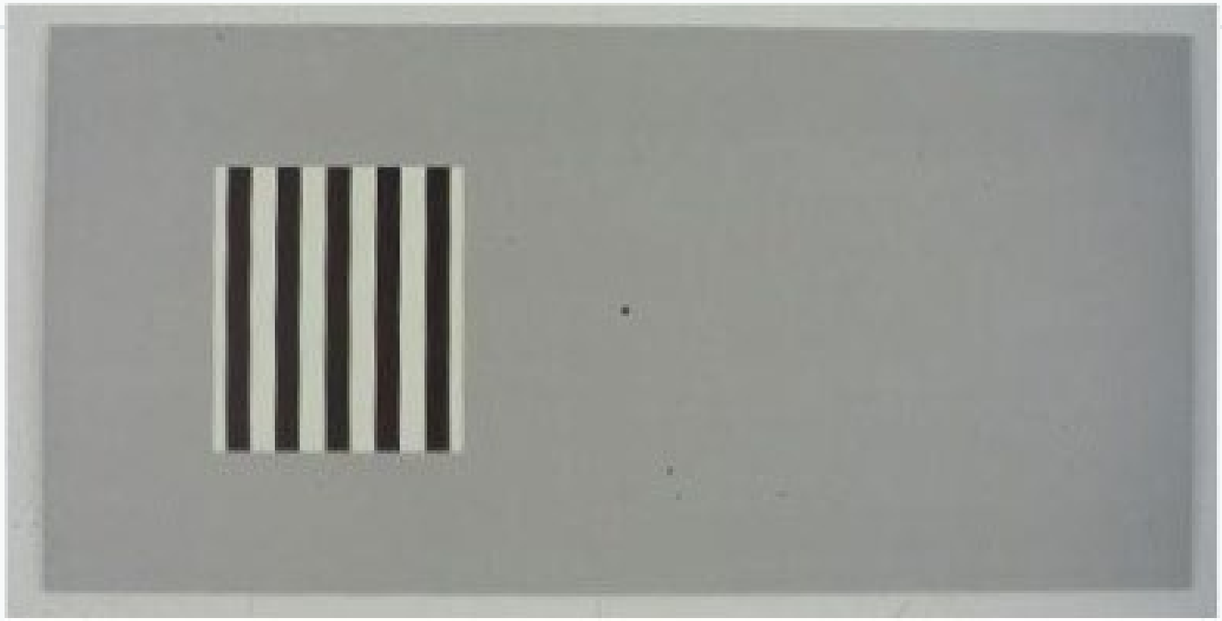
Raja, …Heidary, Front Hum Neurosci 2021; 15; 769259; Jimenez-Gomez et al., Front Hum Neurosci 2022; 16;772353.

VISUAL ACUITY IS IMPACTED IN CVI

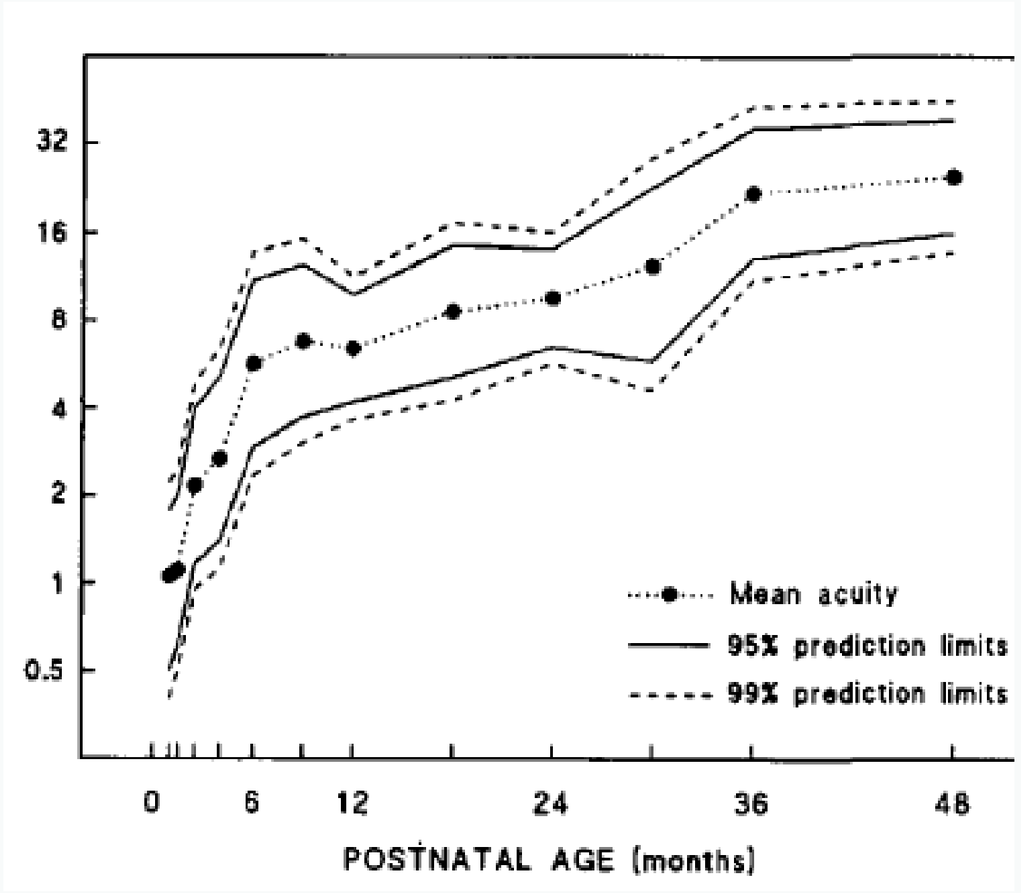
- Visual acuity loss ranges from profound impairment to less commonly normal range
- Children may have visual perceptual difficulties with visual acuity in the normal range
- Case series of 7 children with periventricular leukomalacia
- Normal acuity but abnormal visual perception associated with visuomotor dysfunction

Saidkasimova et al., J AAPOS 2007; 11: 426-430.

TESTING VISION IN PREVERBAL/NONVERBAL CHILDREN



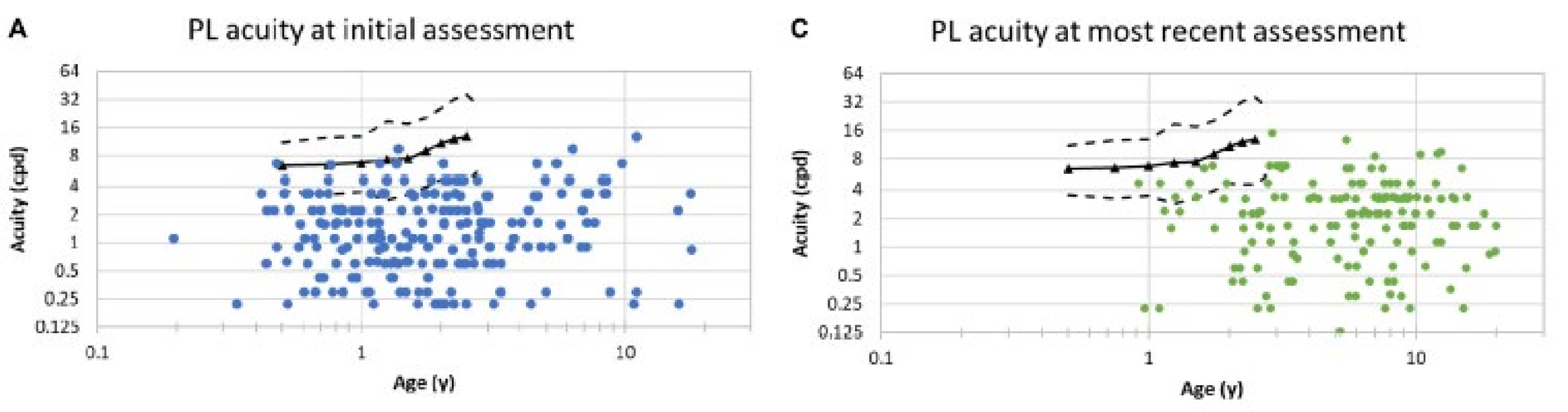
http://dx.doi.org/10.3921/joptom.2009.19



Mayer et al. Invest Ophthalmol Vis Sci. 1995.

VISUAL ACUITY IS IMPACTED IN CVI

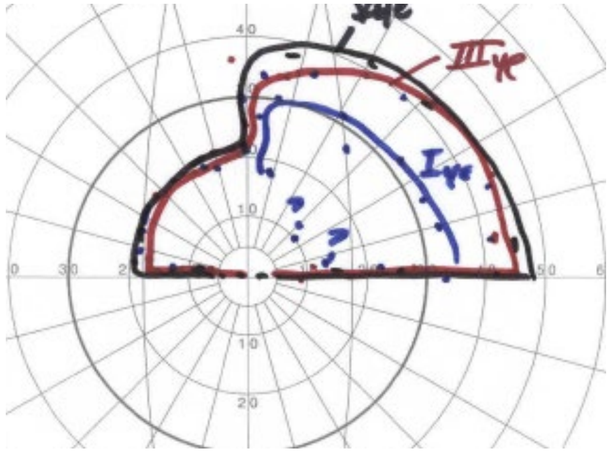
- Study of vision in CVI
  - 218 children
  - Vision was below normal for age
  - Measured vision did improve over time



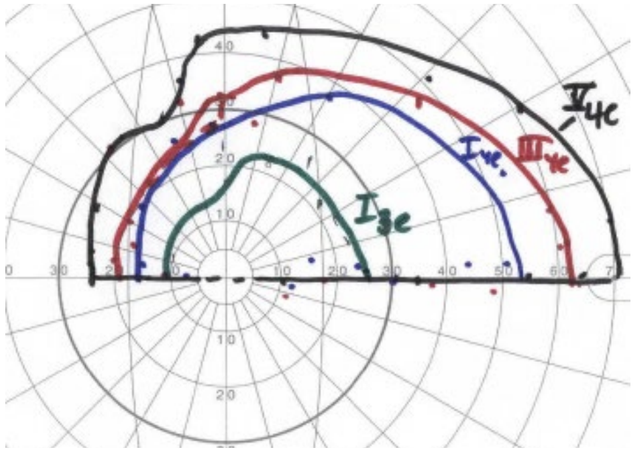
Raja S, Emadi S, Gaier ED, Gise RA, Fulton AB, Heidary G. Front Hum Neurosci 2021.

VISUAL FIELDS MAY BE AFFECTED IN CVI

- Homonymous visual field loss
- Bilateral inferior visual field loss in the setting of periventricular leukomalacia



Left Eye



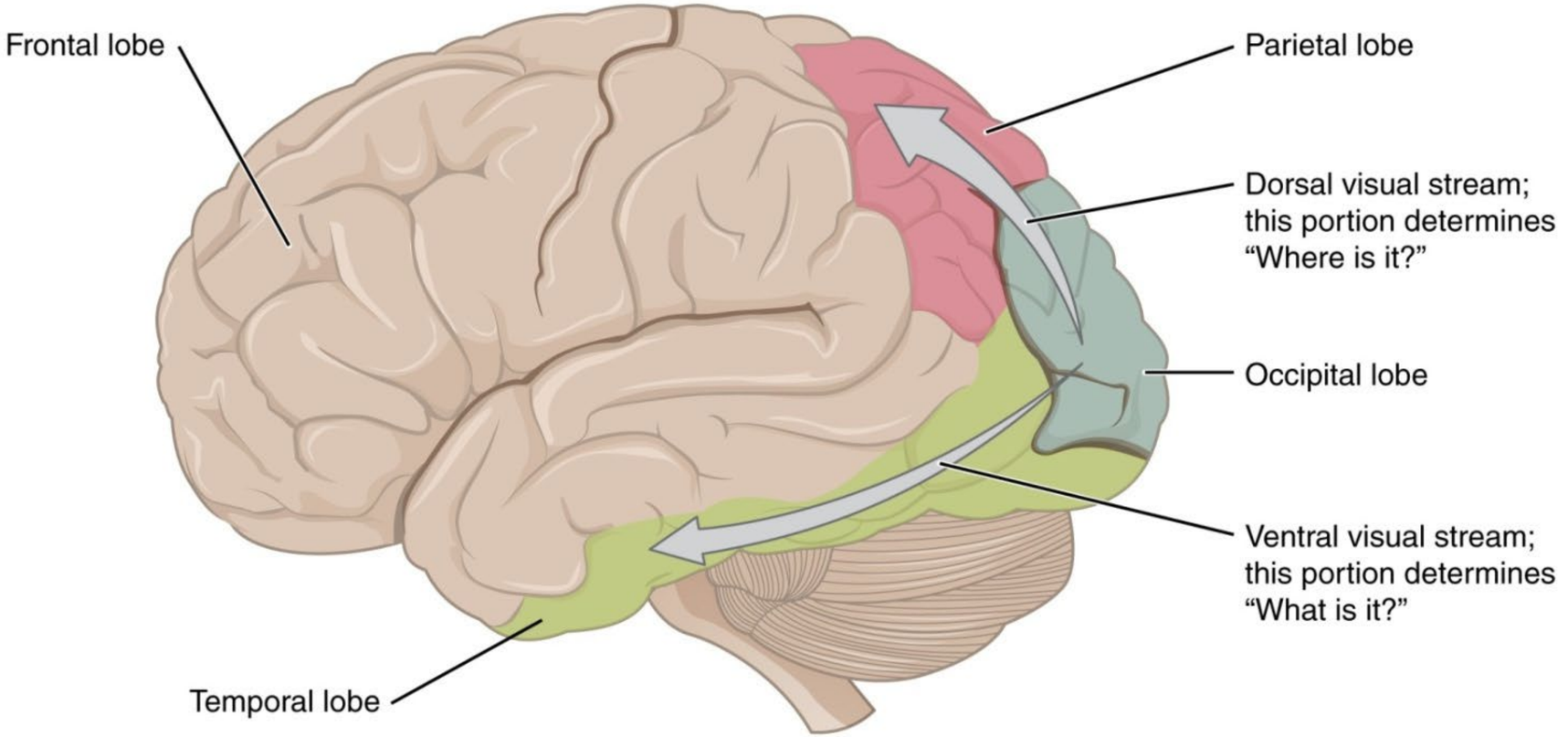
Right Eye

Huo et al, BJO, 1999; Dutton and Jacobsen, 2001.

Efferent Dysfunction is Common

- Strabismus
- Nystagmus
- Gaze palsy
- Difficulty with saccades

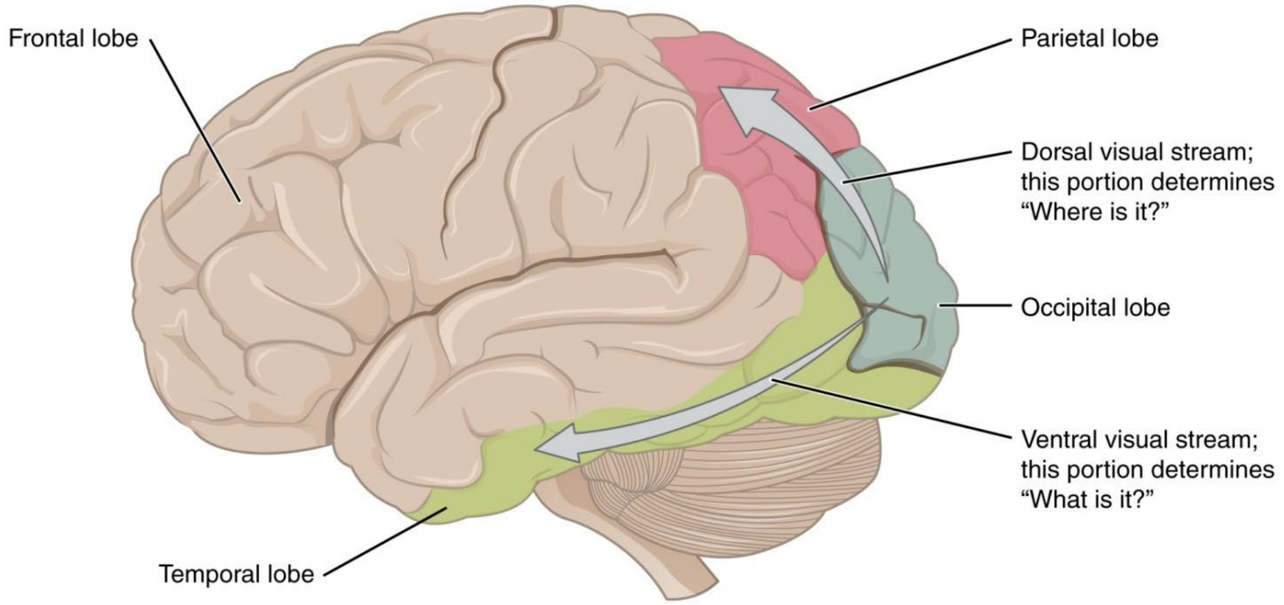
TWO STREAM HYPOTHESIS OF VISUAL PROCESSING



https://voer.edu.vn/file/57853

IMPACT OF CVI ON VISUAL PROCESSING

Dorsal Stream Dysfunction



Ventral Stream Dysfunction

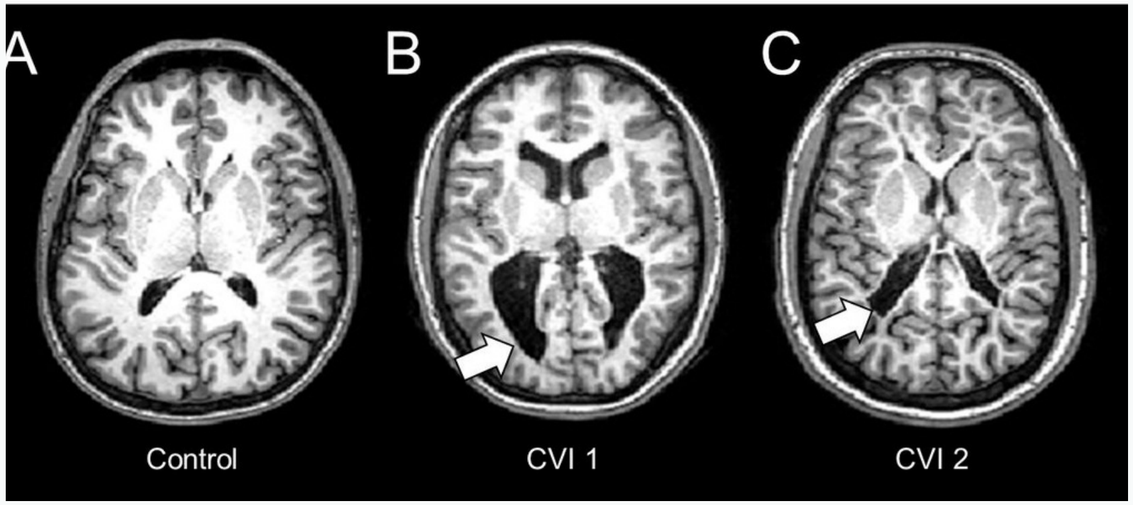
https://voer.edu.vn/file/57853

Difficulty with visual complexity
Inability to sustain visual attention
Difficulties with visual-motor planning

Difficulty with recognition of objects or faces
Difficulty with visual memory

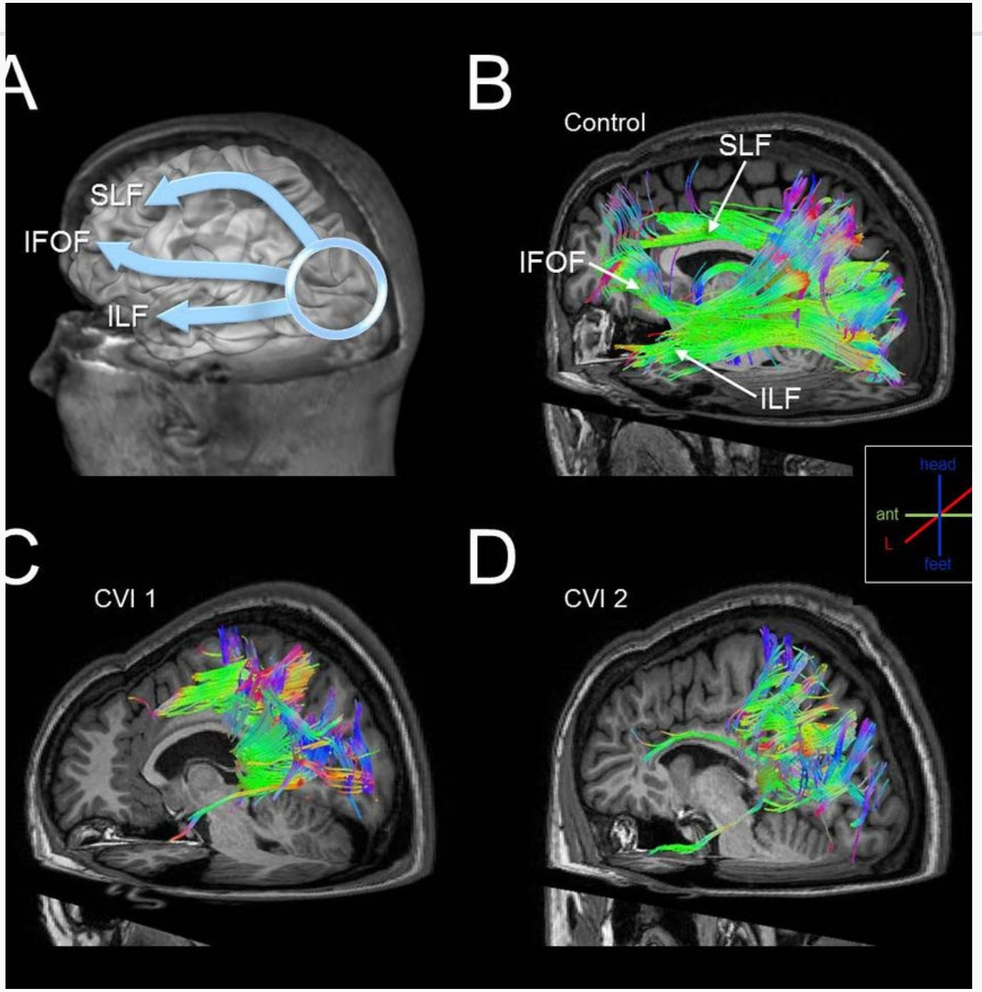
ANATOMIC CONNECTIONS ARE DISRUPTED IN CVI

Axial T1 weighted MRI Images



Case 1
Preterm 32 weeks
PVL

Case 2
Preterm 28 weeks
PVL



Bauer, Heidary, Merabet, JAAPOS 2014.

BEHAVIORAL CHARACTERISTICS

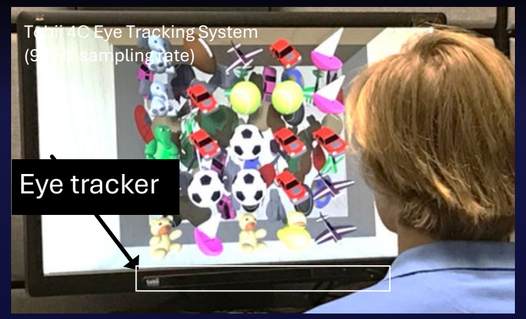
- Light gazing
- Gaze avoidance
- Use of peripheral vision to locate an object
- Increased latency of visual response
- Difficulty with visual complexity
- Difficulty with visual novelty
- Proclivity for a color to see
- Use of movement to see
- Difficulty with distance vision
- Variability of visual attention
  - Exacerbated by concurrent auditory or tactile stimuli

Huo et al, BJO, 1999; Dutton and Jacobsen, 2001.

THE VIRTUAL TOY BOX

1. Searching for target
2. Selective inhibition of distractors

Find:



Courtesy of Lotfi Merabet, OD, PhD

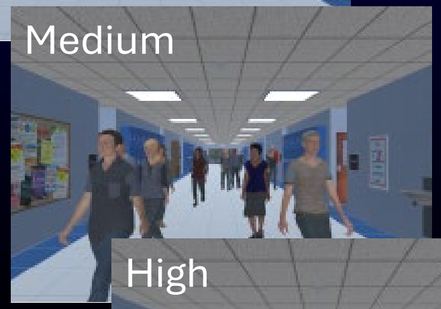
(Good Performance is about knowing where to look AND where not to look)

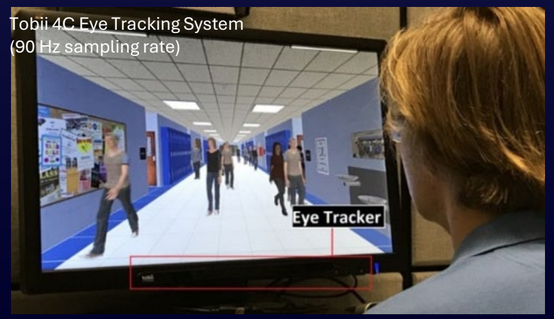
Baseline Fixation/Saccade Control Test

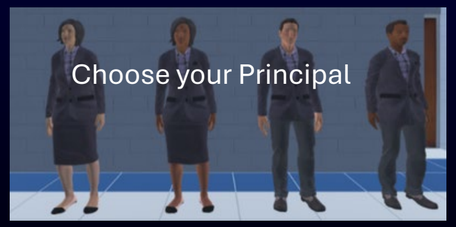
The Virtual Hallway

n=57, Controls=32 (mean age: 20.31 y.o) and CVI=25 (mean age: 17.48 y.o), majority Category 3, Phase III

Task difficulty defined by varying crowd density







Find:

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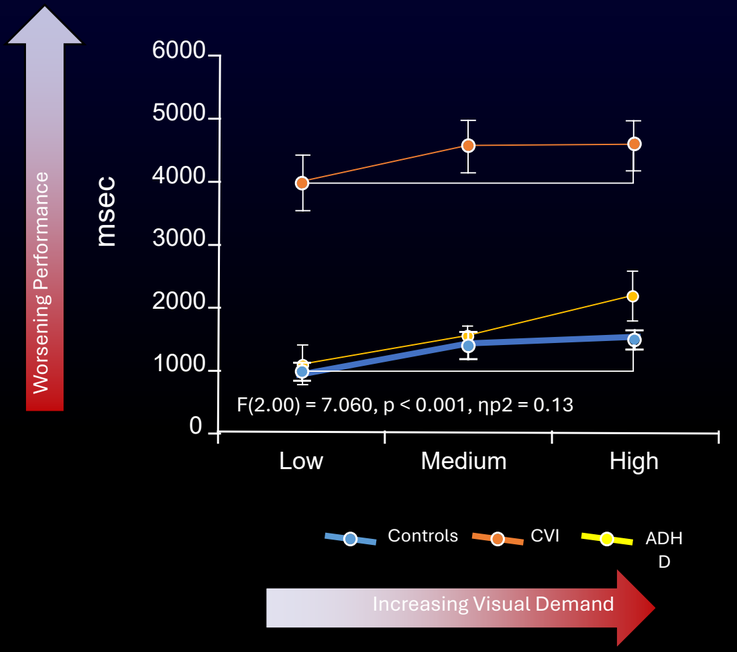
98.96% 88.72%

Off Screen Percentage
Controls: 0.38%
CVI: 0.96%

Reaction Time



Manley et al. Children 2022

ASSESSMENT TOOLS IN CVI

- No gold standard inventory to diagnose and treat exists
- Many assessment tools are available
  - CVI-CR
  - HVFQI
  - Flemish Inventory (Ortibus)
  - Perkins CVI Protocol
  - Austin App
  - Teach CVI

Chang MY, Roman-Lantzy C, O'Neil SH, Reid MW, Borchert MS. BMJ Open Ophth 2022; 7:e001144; Chandna A, Ghahghaei S, Foster S, Kumar R. Frontiers in Hum Neuroscience. 2021; 15:1-14; Ortibus E, Laenen A, Verhoeven J, et al. Screening for cerebral visual impairment: Value of a CVI questionnaire. Neuropediatrics 2011; 42(4) 138-47.

COORDINATED CVI ADVOCACY

- Ophthalmology visit
- Functional vision assessment
- Low vision assessment
- Involvement of a teacher for visual impairment
- Additional services
- OT, PT, Orientation and Mobility
- Social Work
- State services for visual impairment
- Additional Educators
- Input from multidisciplinary team and family

OVERVIEW SUMMARY

- CVI is the leading cause of childhood blindness in developed countries
- The condition is likely underreported
- There are visual and behavioral findings which characterize CVI
- A multidisciplinary approach towards evaluation and treatment is essential
- Recognition of CVI in children with Down Syndrome will facilitate our children receiving the appropriate services to maximize visual function

DS AND VISUAL DISORDERS, INCLUDING CVI

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Associate Professor of Ophthalmology, Clinical Scholar

Children's Hospital Los Angeles

USC Roski Eye Institute

DSMIG symposium, July 24, 2026

FINANCIAL DISCLOSURES: GRANT SUPPORT

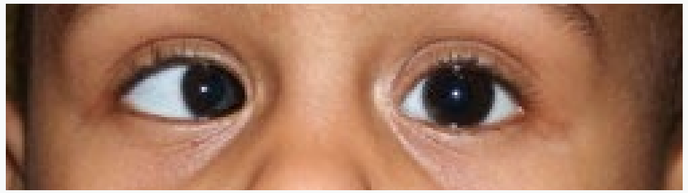
- NIH NEI K23EY033790
- The Saban Research Institute
- North American Neuro-Ophthalmology Society
- Blind Children's Center
- Children's Eye Foundation of AAPOS
- Knights Templar Eye Foundation
- Ingerman/Waltzer Foundation
- Research to Prevent Blindness

No Financial Conflicts of Interest

VISUAL DISORDERS IN DS

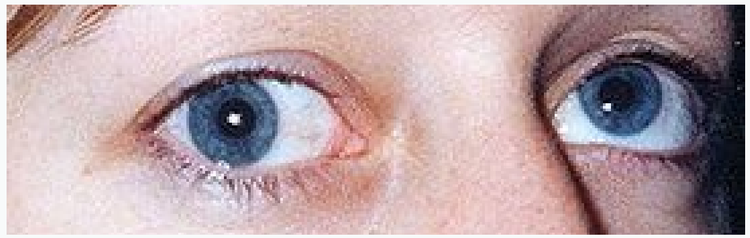
VISUAL DISORDERS IN DS

- Strabismus



Esotropia

Exotropia



Hypertropia

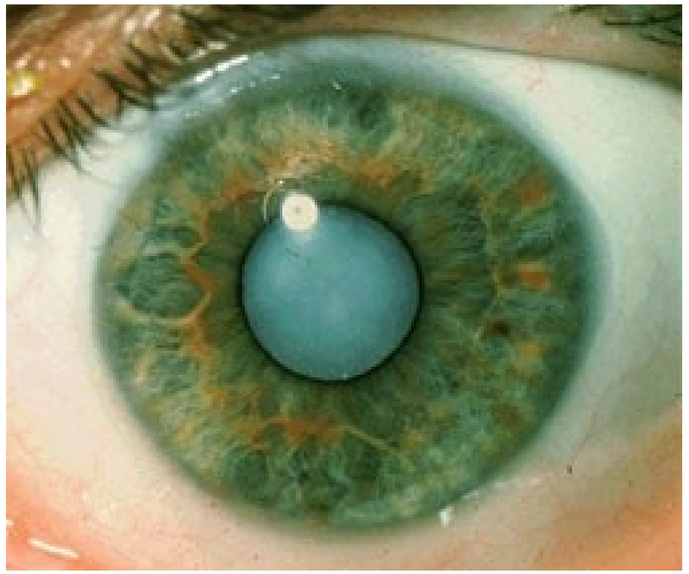
VISUAL DISORDERS IN DS

- Strabismus
- **Refractive Errors**

istockphoto.com

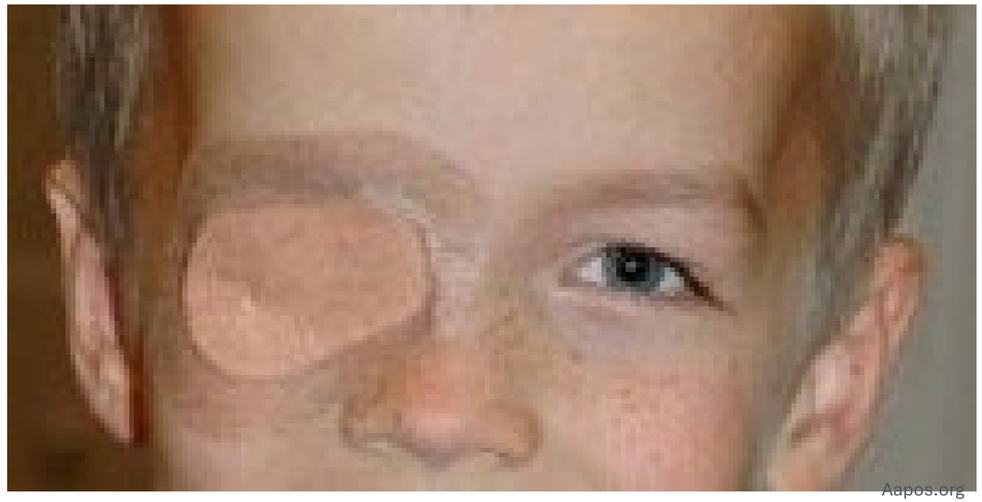
VISUAL DISORDERS IN DS

- Strabismus
- Refractive Errors
- **Cataracts**



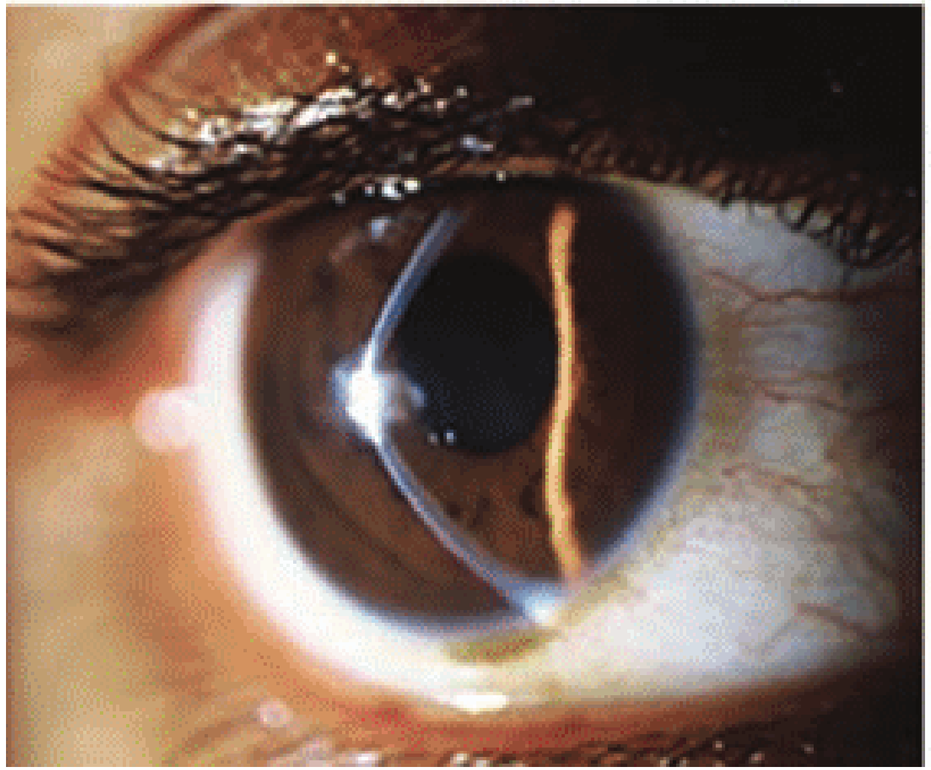
VISUAL DISORDERS IN DS

- Strabismus
- Refractive Errors
- Cataracts
- **Amblyopia**



VISUAL DISORDERS IN DS

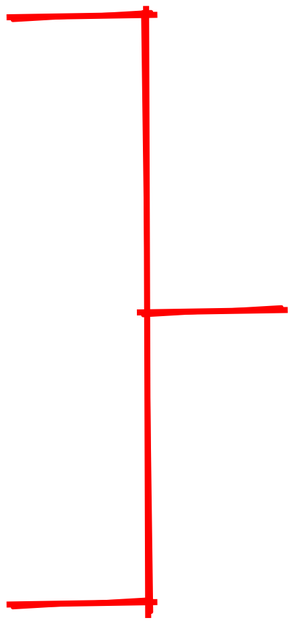
- Strabismus
- Refractive Errors
- Cataracts
- Amblyopia
- Nystagmus
- Blepharitis
- **Keratoconus**



Barbara, Ramez et al. (2014). Keratoconus Expert Meeting, London, 2014. International Journal of Keratoconus and Ectatic Corneal Diseases. 3. 141-158.

VISUAL DISORDERS IN DS

- Strabismus
- Refractive Errors
- Cataracts
- Amblyopia
- Nystagmus
- Blepharitis
- Keratoconus
- **CVI**

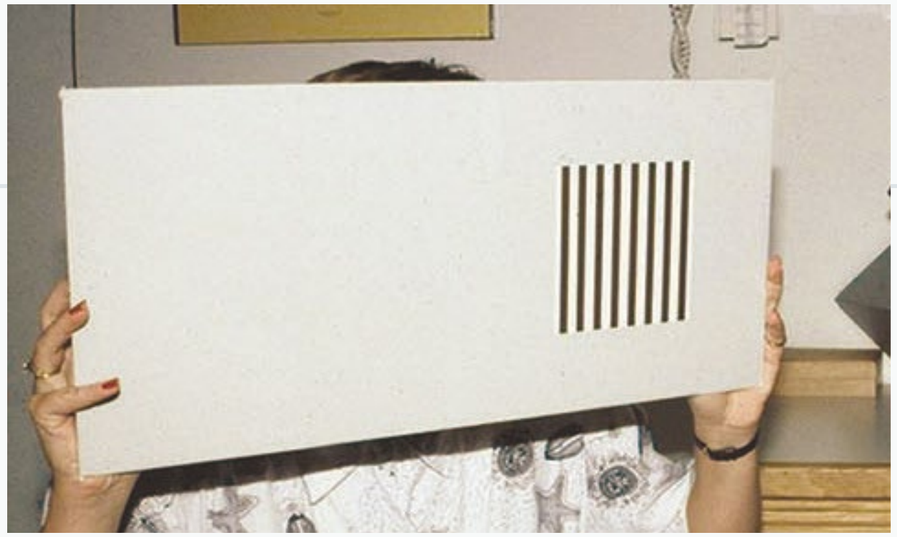


These disorders can be comorbid with CVI

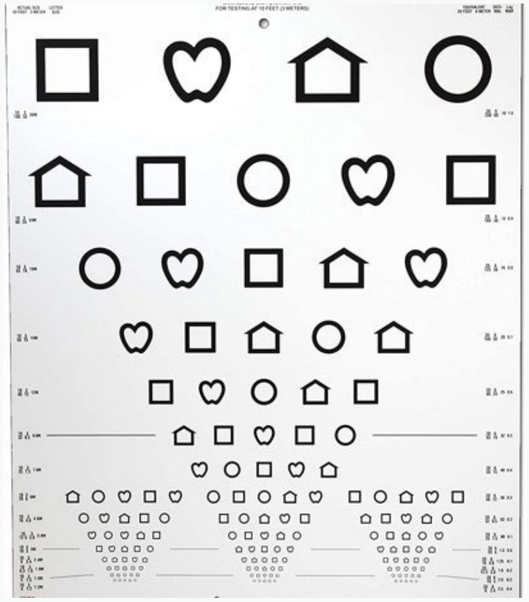
But there must be visual dysfunction not explainable by these disorders to diagnose CVI

CVI ASSESSMENT IN DS

- Basic ophthalmologic examination
  - Visual acuity
  - Visual fields
  - Contrast sensitivity
  - Stereoacuity (binocularity)
  - Ocular alignment
  - Slit lamp examination
  - Fundus examination (ophthalmoscopy)
  - Cycloplegic refraction

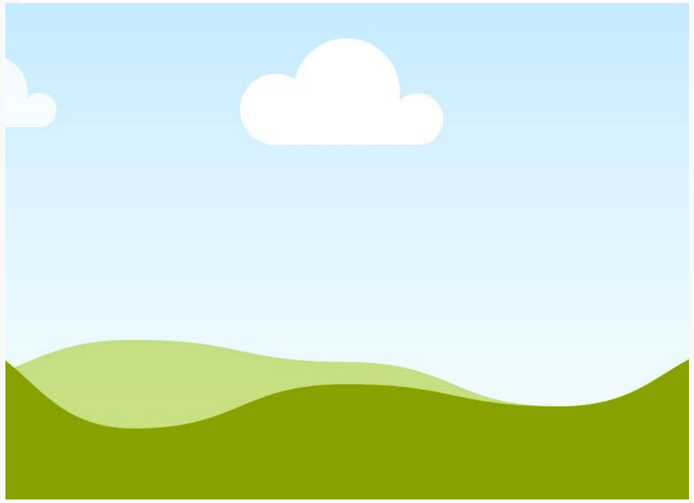


Aao.org



CVI ASSESSMENT IN DS

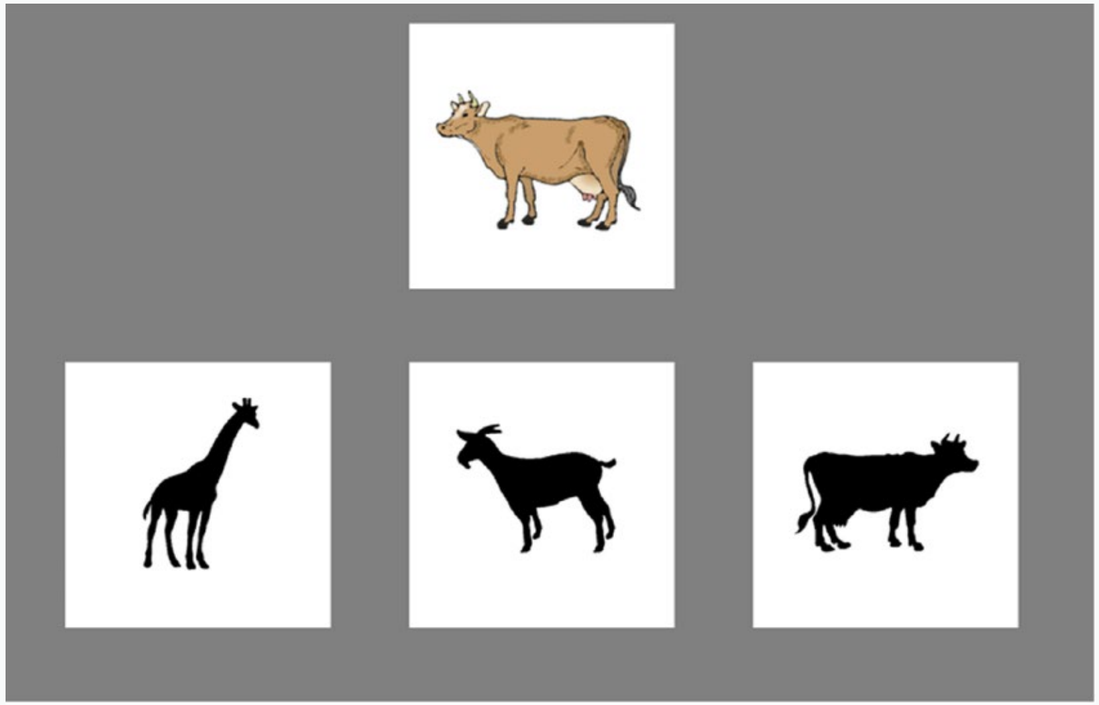
- Basic ophthalmologic examination
- **Non-standardized tests of visual perception**



Leatest.com

CVI ASSESSMENT IN DS

- Basic ophthalmologic examination
- Non-standardized tests of visual perception
- **Standardized tests of visual perception**



CVIT 3-6

Vancleef K, Janssens E, Petré Y, Wagemans J, Ortibus E.

Dev Med Child Neurol. 2020 Jan;62(1):118-124.

CVI ASSESSMENT IN DS

- Basic ophthalmologic examination
- Non-standardized tests of visual perception
- Standardized tests of visual perception
- **CVI questionnaires**

Screening for Cerebral Visual Impairment: Value of a CVI Questionnaire

E. Ortibus[1,4], A. Laenen[2], J. Verhoeven[1], P. De Cock[1], I. Casteels[3], B. Schoolmeesters[4], A. Buyck[5], L. Lagae[1]

Flemish CVI Questionnaire

Higher Visual Function Deficits in Children With Cerebral Visual Impairment and Good Visual Acuity

Arvind Chandna[1,2], Saeideh Ghahghaei[1], Susan Foster[2] and Ram Kumar[2]*

HVFQI and CVI Inventory

Rasch analysis and targeting assessment of the teach-CVI survey tool in a cohort of CVI patients

Jem Martin[1*], Chris Bradley[2], Barry S. Kran[1] and Nicole C. Ross[1,3]

Teach CVI

CVI ASSESSMENT IN DS

- Basic ophthalmologic examination
- Non-standardized tests of visual perception
- Standardized tests of visual perception
- CVI questionnaires
- **Functional vision assessments**

Chang MY, et al. Ophthalmol Sci. 2026 May 12;6(7):101233.

Zatta MC and Willems I. J Vis Impair Blind. 2024 Nov;118(6):465-476.

CVI Range (for Clinical Research)

Perkins CVI Protocol

RISK OF CVI IN DS

Behavioural Features of Cerebral Visual Impairment Are Common in Children With Down Syndrome

Gemma J. Wilton [1], Rhodri Woodhouse [1], Valldeflors Vinuela-Navarro [1,2], Rachel England [1] and J. Margaret Woodhouse [1]*

Front Hum Neurosci. 2021 Jun 14;15:673342.

DSMIG-USA® Down Syndrome Medical Interest Group ANNUAL symposium July 23-25 Orlando, Florida

FIVE QUESTIONS FOR CVI SCREENING

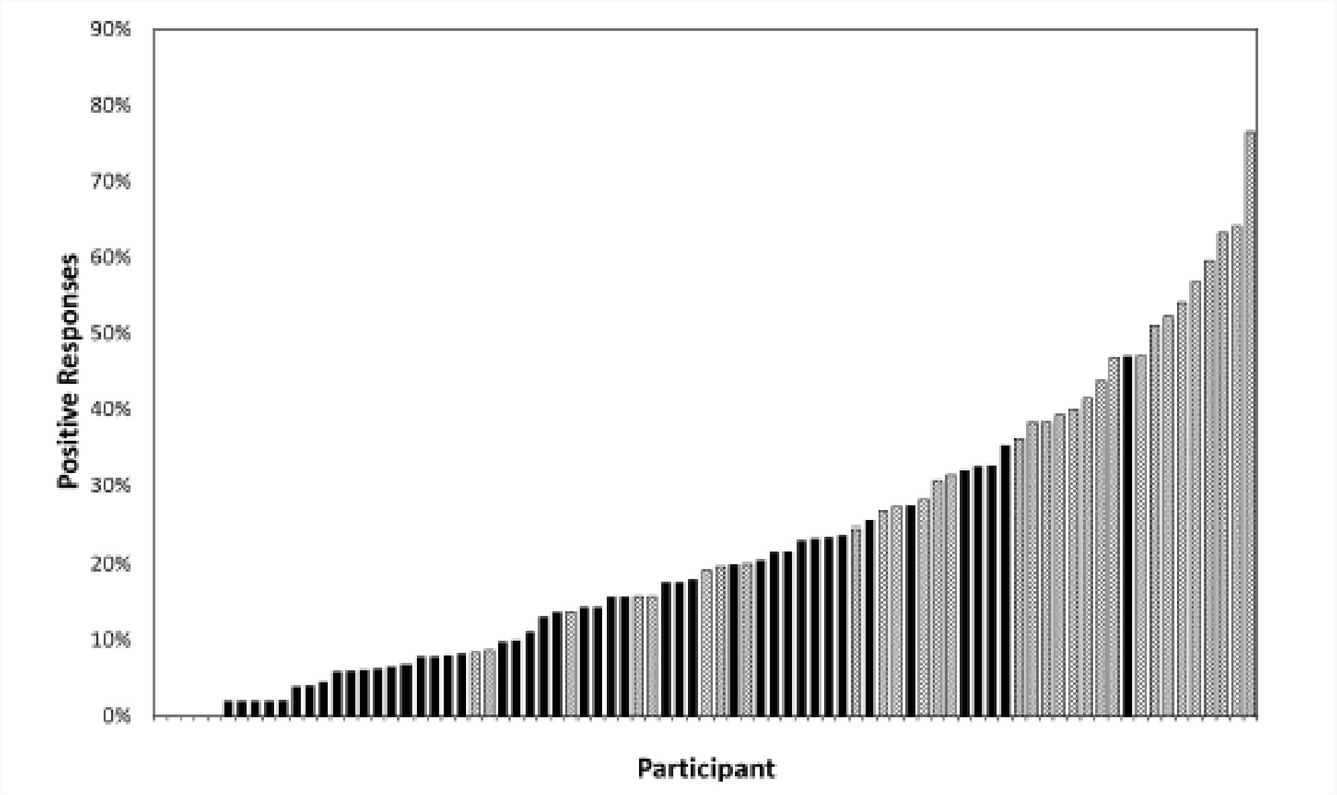
- **Does your child have difficulty:**
  - Walking down stairs?
  - Seeing things that are moving quickly, such as small animals?
  - Seeing something that is pointed out in the distance?
  - Locating an item of clothing in a pile of clothes?

- Does your child find copying words or drawings time-consuming and difficult?

Positive screening:
"Always" or "Often" response
to at least 3 of 5 questions

RESULTS

- **38%** of children (4-17 years) with DS screened positive for CVI
- No clear cutoff to detect CVI in children with DS



Positive CVI screening

Negative CVI screening

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ANNUAL symposium
July 23-25
Orlando, Florida

VISUAL PERCEPTUAL CHALLENGES IN DS

Profiles of visual perceptual functions in Down syndrome

Yi-Ting Wan [a], Ching-Sui Chiang [a], Sharon Chia-Ju Chen [b], Chih-Chung Wang [c], Yee-Pay Wuang [a,c,*]

Research in Developmental Disabilities 37 (2015) 112–118

Spatial-simultaneous and spatial-sequential working memory in individuals with Down syndrome: The effect of configuration

Barbara Carretti [a,*], Silvia Lanfranchi [b], Irene C. Mammarella [b]

Research in Developmental Disabilities 34 (2013) 669–675

VISION-DS STUDY IN LOS ANGELES

- Vision In SyndrOmic Neurodevelopmental disorders – Down syndrome
- Prospective study of 110 children (4-12 years) with DS
  - Eye examination by pediatric neuro-ophthalmologist
  - Visual perception testing
  - CVI questionnaires
  - Functional vision testing (CVI Range-CR) in children diagnosed with CVI
  - **Eye tracking**

VISION-DS STUDY IN LOS ANGELES

- **Overall goal:** to determine if eye tracking can detect and characterize CVI in children with DS.

- **Impact:** Since eye tracking is objective, quantitative, and scalable, validation of an eye tracking technique to detect CVI in children with DS can facilitate widespread screening, enabling early diagnosis and interventions.

EYE TRACKING LAB AT CHLA

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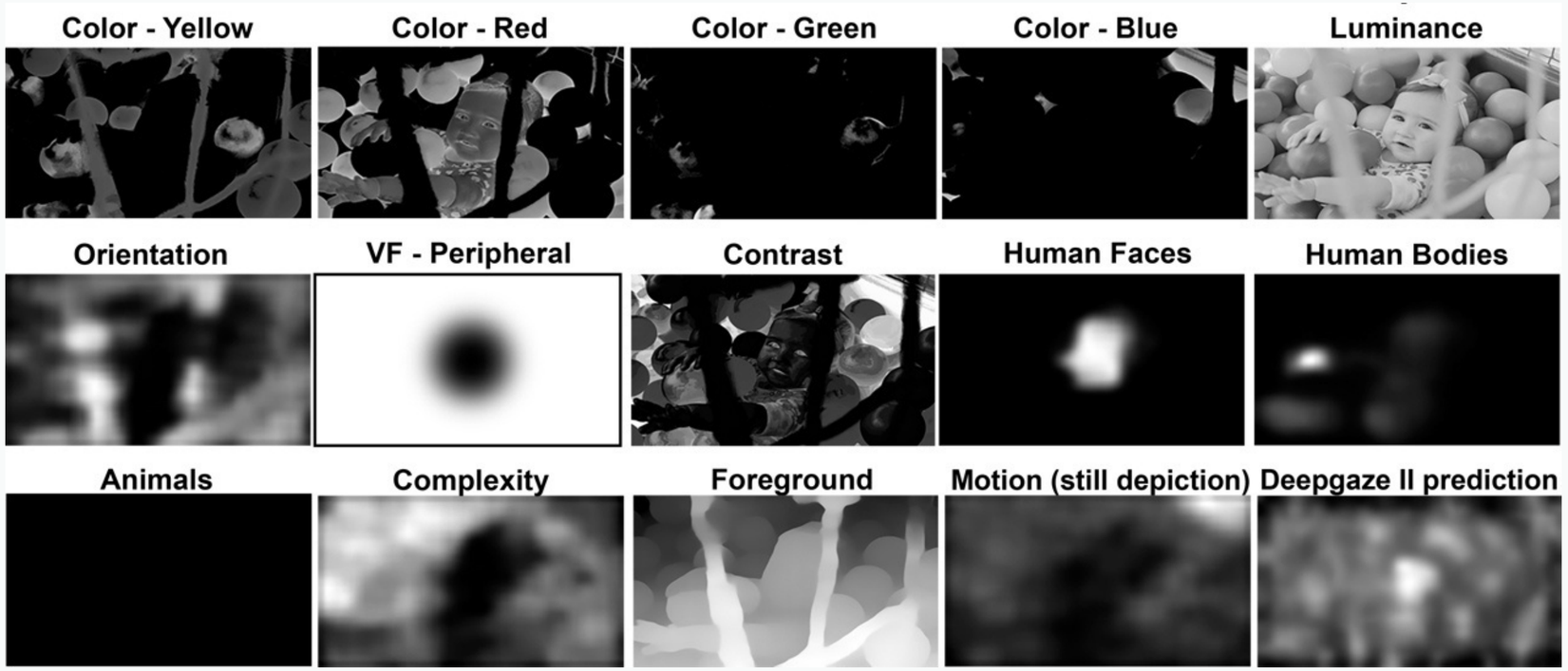
ANNUAL symposium

July 23-25
Orlando, Florida

SET-CVI

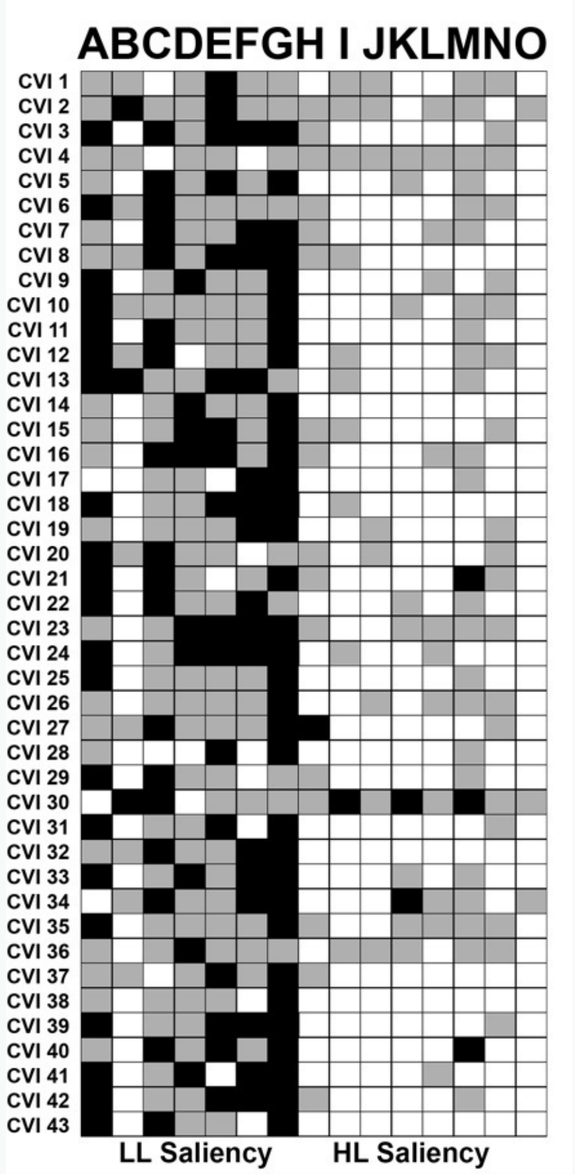
- Saliency analysis of Eye Tracking for CVI
- Generative-AI enabled technique to assess visual attention

GenAI prompt



Saliency Maps

SET-CVI EYE TRACKING SIGNATURES



Lower-Level Saliency

A: Color - Yellow
B: Color- Red
C: Color - Green
D: Color - Blue
E: Luminance
F: Orientation
G: Visual field (peripheral)
H: Contrast

Higher-Level Saliency

I: Human Faces
J: Human Bodies
K: Animals
L: Complexity
M: Foreground
N: Motion (still depiction)
O: Deep Gaze (Typical adult visual attention)

Above Normal
Within Normal
Below Normal

Matsunaga K, Avramidis K, Borchert MS, Narayanan S, Chang MY. Ophthalmol Sci. 2026 Jan 21;6(4):101081.

VISION-DS EYE TRACKING EXAMPLE

“Blue”

Lower-level

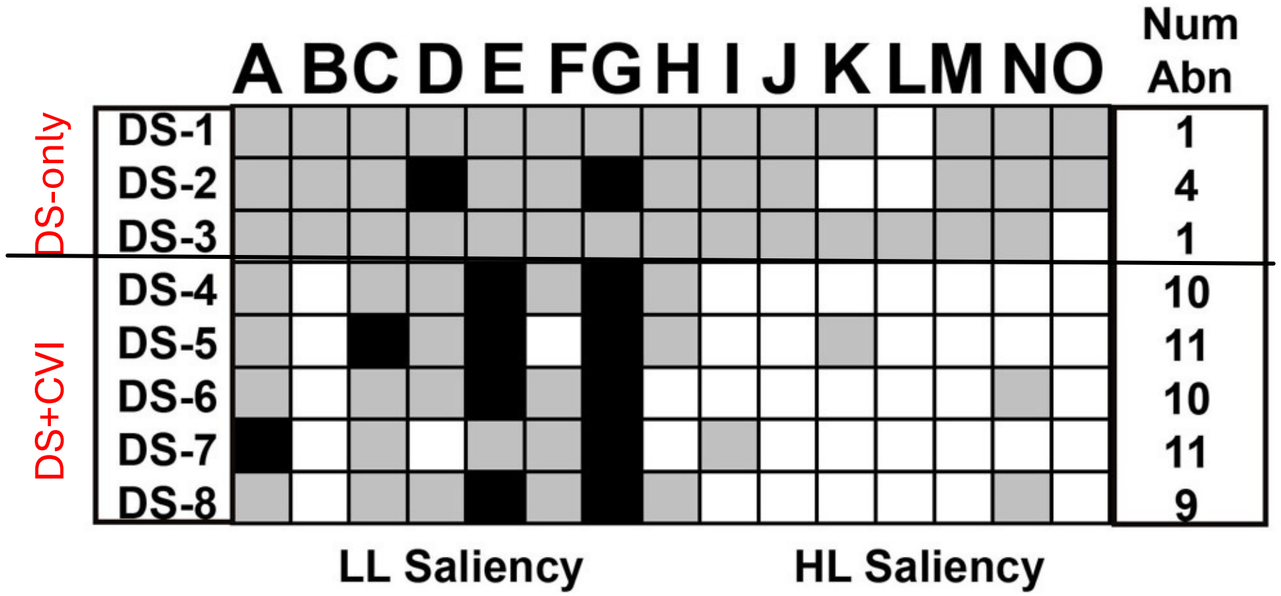
“Moving”

Higher-level

DS without CVI

DS with CVI

SET-CVI Eye Tracking Signatures



Legend

Above Normal | Within Normal | Below Normal

Lower-Level Saliency

A: Color - Yellow
B: Color- Red
C: Color - Green
D: Color - Blue
E: Luminance
F: Orientation
G: Visual field (peripheral)
H: Contrast

Higher-Level Saliency

I: Human Faces
J: Human Bodies
K: Animals
L: Complexity
M: Depth (2D depiction)
N: Motion (still depiction)
O: Deep Gaze (Typical adult visual attention)

SUMMARY

- Visual disorders are common in individuals with DS.
- To diagnose CVI, visual dysfunction must be worse than expected by any co-morbid ophthalmologic disorders.
- Based on questionnaires, children with DS have an increased risk of CVI (~38%).
- Eye tracking may be useful to detect and characterize CVI in children with DS (research ongoing).

VISiON-DS interest form

ACKNOWLEDGMENTS

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- **CVI and DS patients and families**

DSMIG-USA® Down Syndrome Medical Interest Group ANNUAL symposium July 23-25 Orlando, Florida

WHAT DOES DS+CVI LOOK LIKE?

Seeing Cerebral/Cortical Visual Impairment (CVI) in Down Syndrome:

Functional Deafblindness

Elizabeth Boatwright, MD

Internal Medicine-Pediatrics, Parent

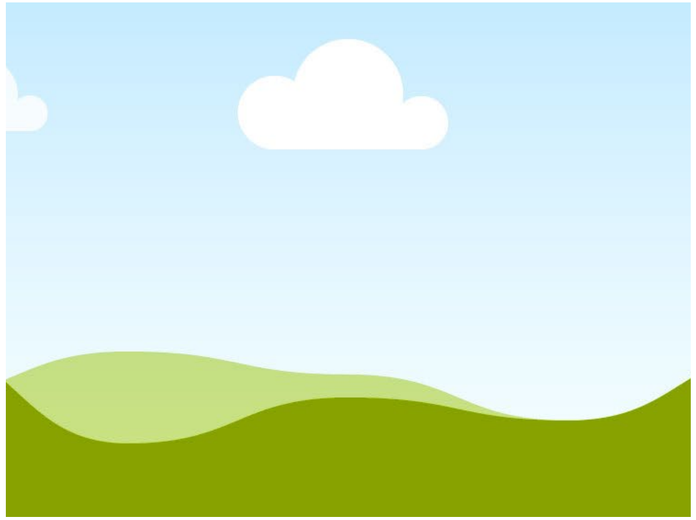
Contributions from Jennifer Saenz, DO and DSMIG DS+CVI Workgroup

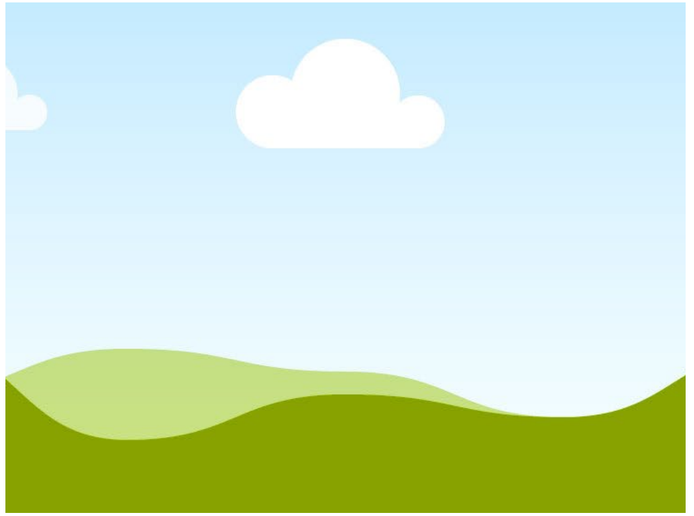
DSMIG-USA® Down Syndrome Medical Interest Group

ANNUAL symposium

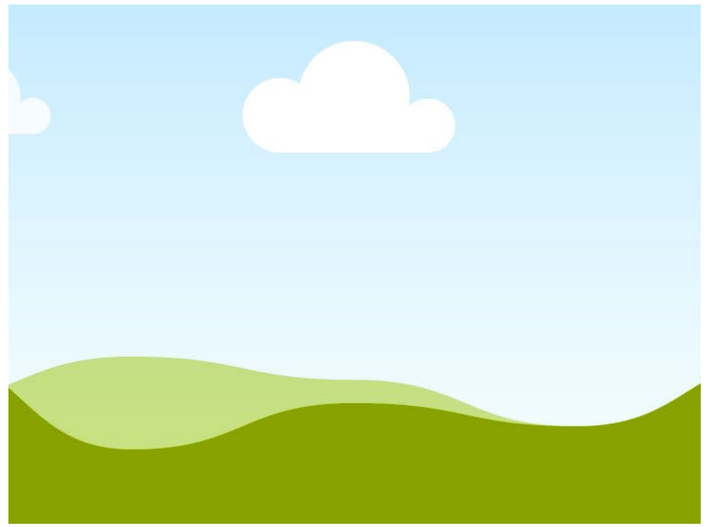
July 23-25 Orlando, Florida

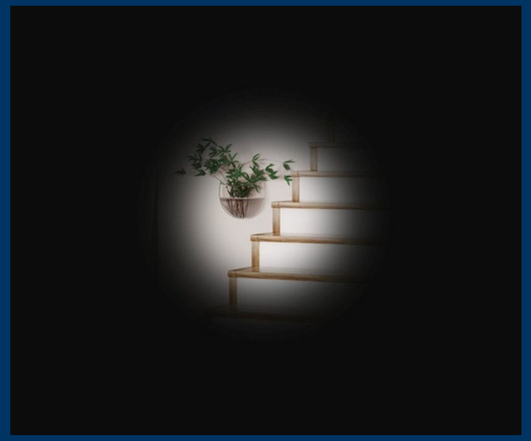
SIGNS OF REDUCED VISUAL AND AUDITORY ACCESS IN DS MAY BE SUBTLE

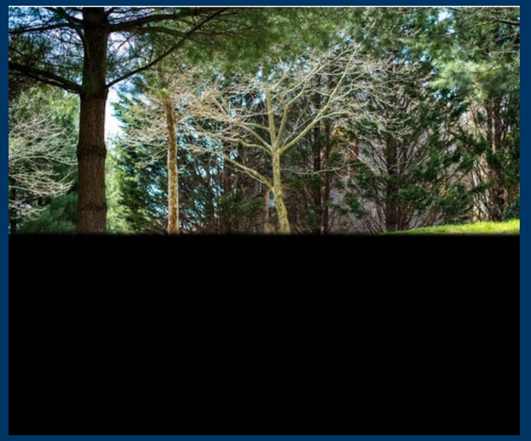




- Not looking into the distance/following a point;
- Slow to turn to her name;
- Startle behavior with sudden loud sounds;
- Not consistently responding to someone across the room **but**
- **interactive up close**







Examples of what people with CVI might see

From Perkins School for the Blind, CVI Now

For simluation videos see https://cviscotland.org/mem_portal.php

THE VISUAL-AUDITORY MISMATCH IN DOWN SYNDROME + CVI:

Picturing DS+CVI/ Functional Deafblindness

Observations from my Photo Library:

1. Stress and anxiety in an unstable visual/auditory world
2. The power of touch
3. Prolonged interdependence

1. Stress and anxiety in an unpredictable, inaccessible world

Photo deleted:
Shows girl with DS sitting on the ground looking down, sister standing
“Drop and flop”

Note: consider the behavior with a deafblind lens; what could be happening from a vision standpoint?

Photo deleted:
Teen with DS standing with family for a group photo, pulling long blonde hair of her sister standing to her right

Note: teen with DS has CVI and a reduced R visual field; consider what the visual experience may be if sudden flow of blonde hair appears in visual field unexpectedly…reactive grab

(Example: A young boy with CVI had been labeled as “aggressive” because of punching in the hallway - when it was determined it was always on the side with a reduced visual field, accommodations were made and punching stopped)

Photo deleted:
young girl with DS crying in bright snow on sled
“meltdown”

Photo deleted:
Girl with DS at playgound with dazed look
“visual overwhelm”

Gymnastics and Cheer

Photo deleted:
Three kids with DS, one looking stressed, others relaxed in gym posing for photos

Photo deleted:
Same kids, stressed one looking away
“look away to listen”

Photo deleted:
Girl with DS leaning into peer mentor, holding hands,
looking more reassured

Photo deleted:
Same girl with DS and her peer mentor, in a quiet part of the gym, practicing moves and showing that earlier drop and flop, stress behavior and non-participation were NOT due to cognitive issues or musculoskeletal weakness, but to access issues and competing sensory input causing visual processing challenges to worsen

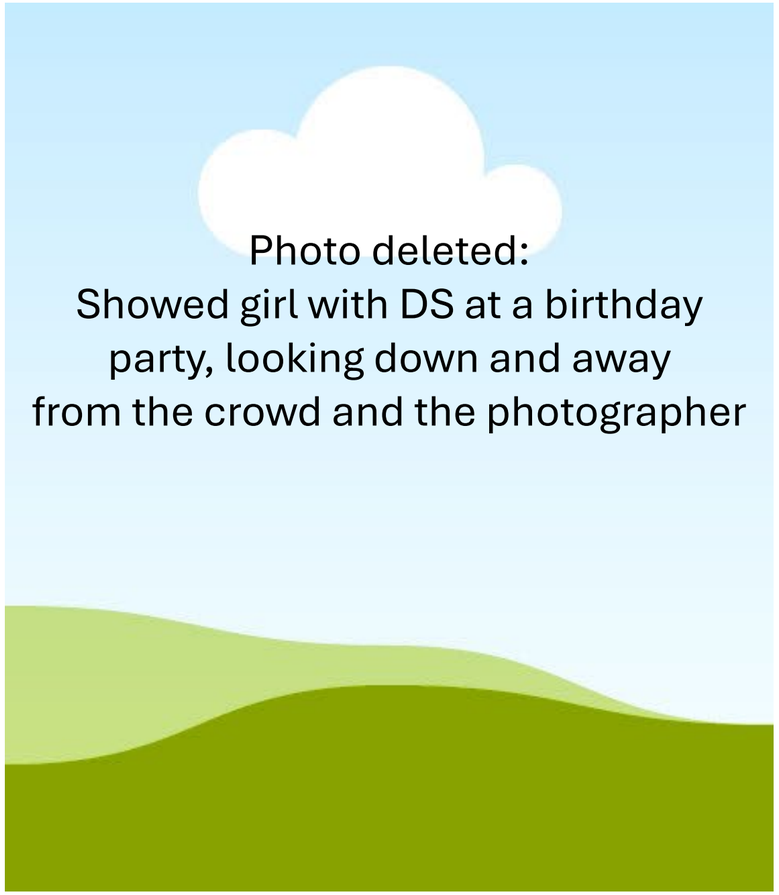
Does your child have trouble in busy, noisy environments?

Do you avoid going to busy stores or other community locations with your child? Why?

How does your child behave at group gatherings or birthday parties? Group sports? Do they love dances?

Did you bring your child to NDSC?

Does your child do better 1:1?



2. A Powerful Tactile Sense: Connection

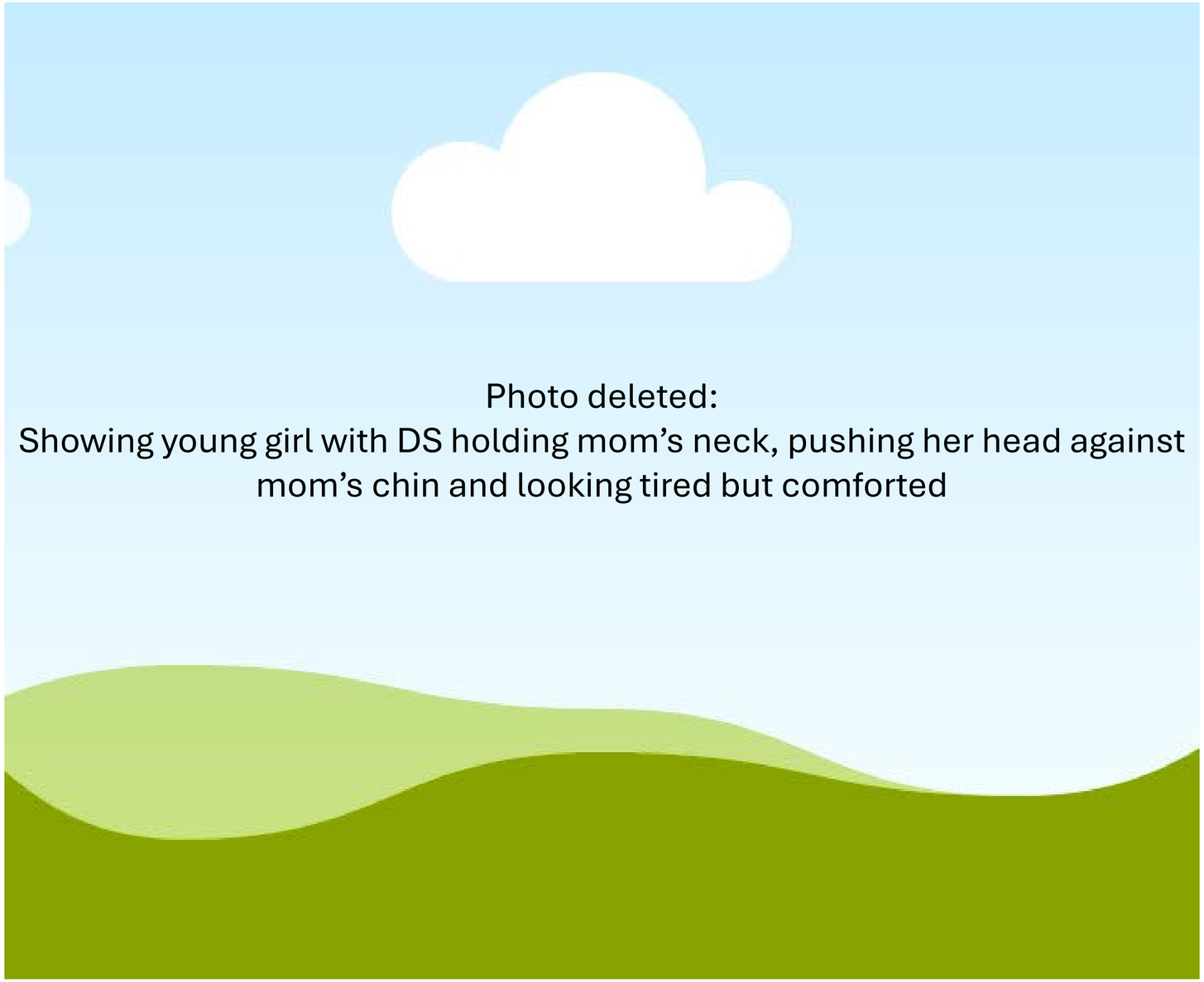


Photo deleted:

Girl with DS standing and leaning against her sister in front of a car, holding hands

Photo deleted:

Girl with DS sitting at a library table with a friend who is reading a book open in front of them; girl with DS is placing her hand on her friend’s arm, looking away from the book and smiling (listening to the story)

Photo deleted:

Girl with DS smiling and interacting with an adult (out of photo), singing and clapping

Photo deteled:

Girl with DS standing with her grandmother, leaning against her and holding her hand

Photo deleted:

GIrl with DS held by her dad, looking away from his face but holding her hands to his cheeks, feeling his facial stubble.

Photo deleted:

Girl with DS surrounded by sisters and cousins, seated at an outdoor picnic table in the summer, banging both hands on the table (and sister and cousin also playing the “banging game” and singing/smiling)

Note: banging is a common deafblind behavior, used to get someone else’s attention (ie cafeteria)

Photo deleted:

Girl with DS sitting cross -legged, knee to knee with a boy who is also sitting cross -legged on the floor, both tapping their fingers together (girl is not looking up)

Note: common deafblind etiquette is sitting knee -to-knee or toe-to-toe with a communication partner, to orient in space.

Note: family would constantly work on “personal space” with this tactile behavior, not aware it was a sign of CVI and functional deafblindness.

Implications:

- Importance of tactile learning
- Tactile defensiveness with hand-over-hand vs hand-under-hand

3. Prolonged Interdependence

Photo deleted:

Preteen with DS holding hands with her grandmother

Prolonged interdependence as code for “delayed milestones” or “family giving help at ages beyond when you’d expect the need for help”

Photo deleted:

baby with DS sitting

“observer type” when it came to gross motor development (versus “motor driven type”) - from PT Pat Winder’s categories in her book, Gross Motor Skills for Children with DS

Photo deleted:

Young girl with DS holding a high bar and being helped to hang and raise her legs (not looking at the bar and clearly being fully assisted)

Photo deleted:

Young girl with DS being assisted with walking

up a ramp by her dad

Note: our daughter had late gross motor milestone acheivement, not walking until over 3 yrs old

What might have happened if she had been given a mobility device from a young age? (see next video)

Photo deleted:

Young girl (8 yr old) being assisted by her brother to dye an Easter egg, as he holds her hand to help dip while sister stands by and encourages

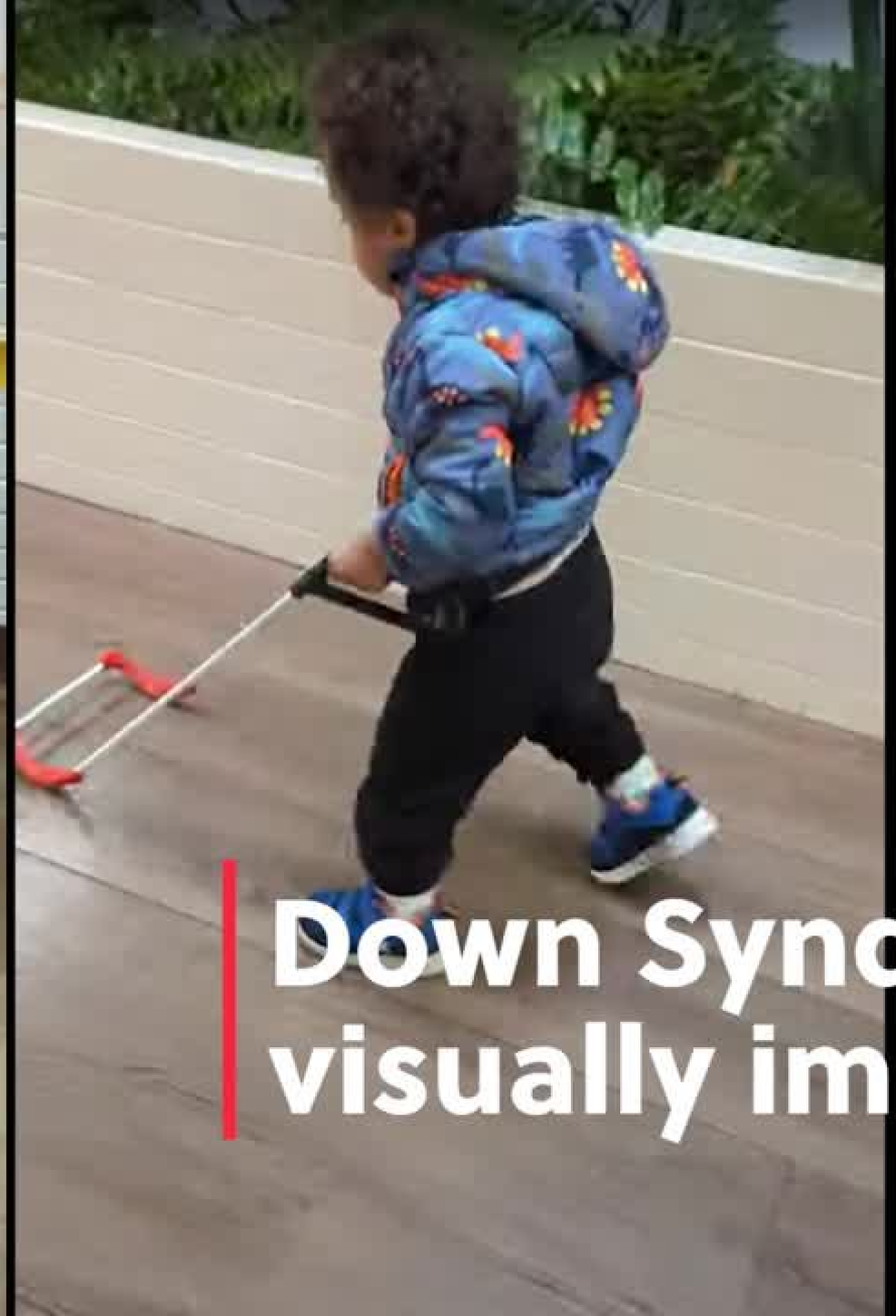
Photo deleted:

Girl with DS roughly 9 yrs old

getting a piggy back ride from her sister

Note: family often assisted our daughter and compensated when we knew certain environments or tasks would be challenging to her - not consciously thinking about access, but avoiding behaviors that may result from that environment or task/challenge.

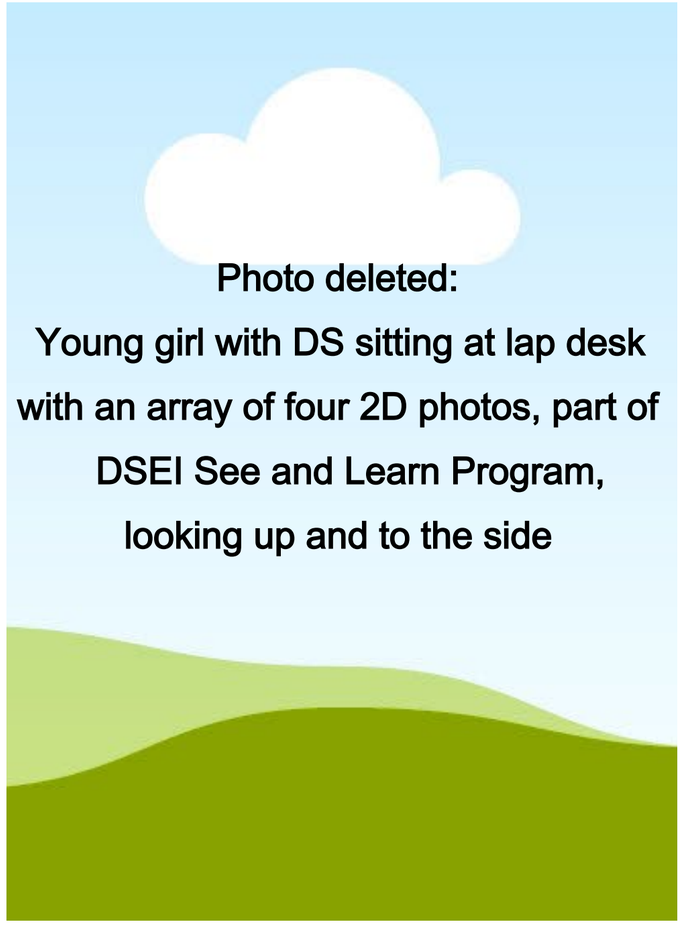
Strategies: Mobility Assist



Down Syndrome and visually impaired

Educational challenges from CVI/ functional deafblindness

- ***Inconsistent*** **recognition**
  items, 2D pictures, fonts, words
- Inconsistent/slow vocabulary and language development
- Challenges with writing, tracing, coloring
- Challenge using multiple sensory channels at once and
- Variable visual attention
  - easy to miss in the educational setting



Video deleted:
Shows girl with DS facing her teacher and showing inconsistent visual attention and teacher not noticing, thinking she is watching and understanding. Hand -over-hand writing/circling while not watching.

Note: it is easy to miss lack of visual attention in the educational setting, and to attribute slow academic progress to cognitive challenges rather
than access issues.

Implications of DS+CVI:

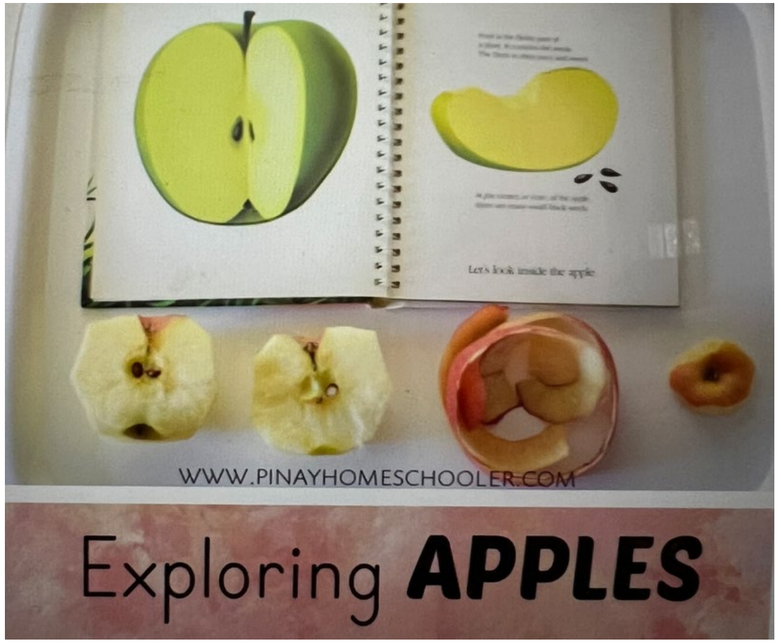
- **Access issues** may be misunderstood as **cognitive or developmental issues**
- Unsupported access issues **will** lead to delays
  - Require deafblind supports
  - Mindset change: from “developmental delay” to “develpmental barrier”

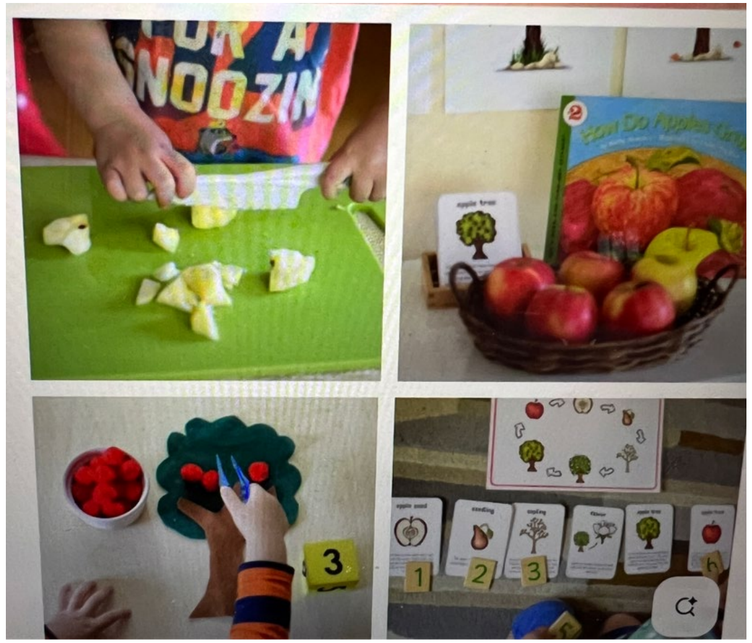
Helpful strategies to support DS+CVI

- Reduce Complexity:
  - Single sensory channel input (eyes or ears)
  - Clear the clutter

Helpful strategies to support DS+CVI

- Explicit teaching (sounds, salient visual features, single channel, multisensory)
- Experiential teaching (3D)



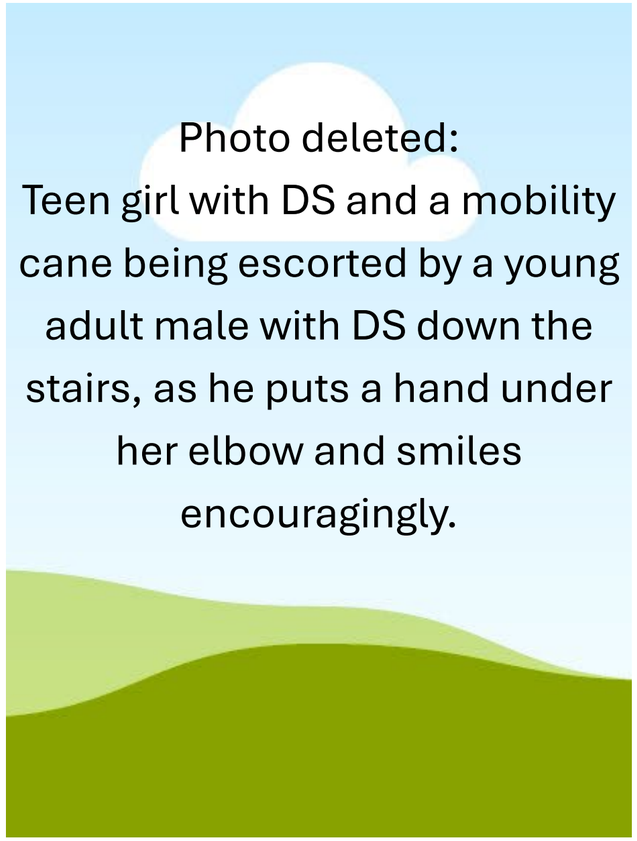


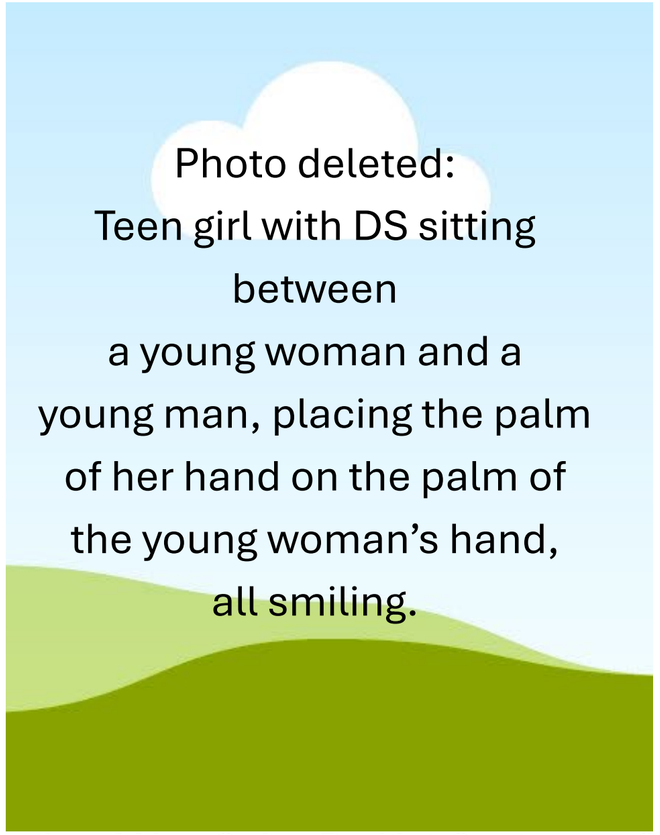
Helpful strategies to support DS+CVI

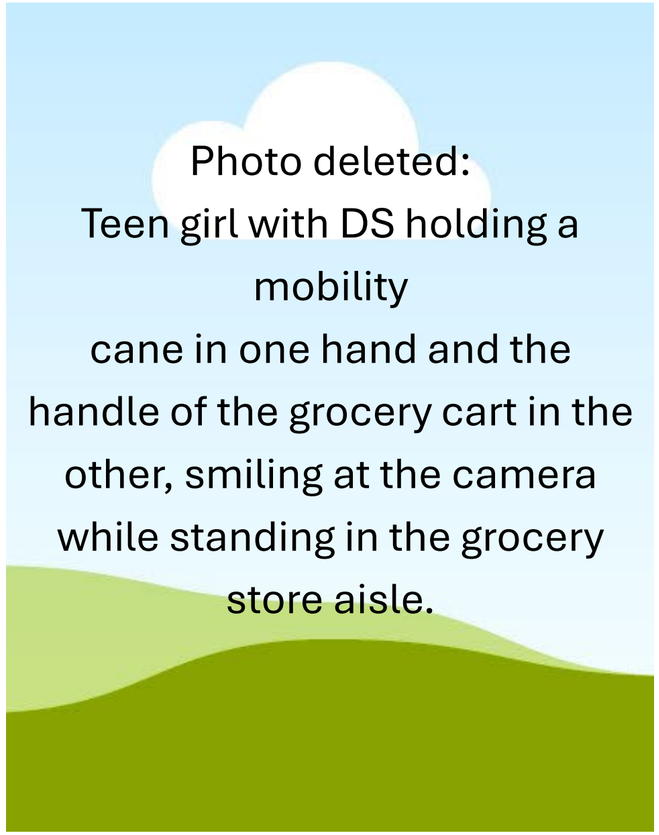
- Tactile aids
  - ASL/haptics
  - 3D objects in routine
  - Cane use for O&M

Goals of deafblind supports

- Provide access: to learning, skills, mobility, communication, community
- Healthy interdependence





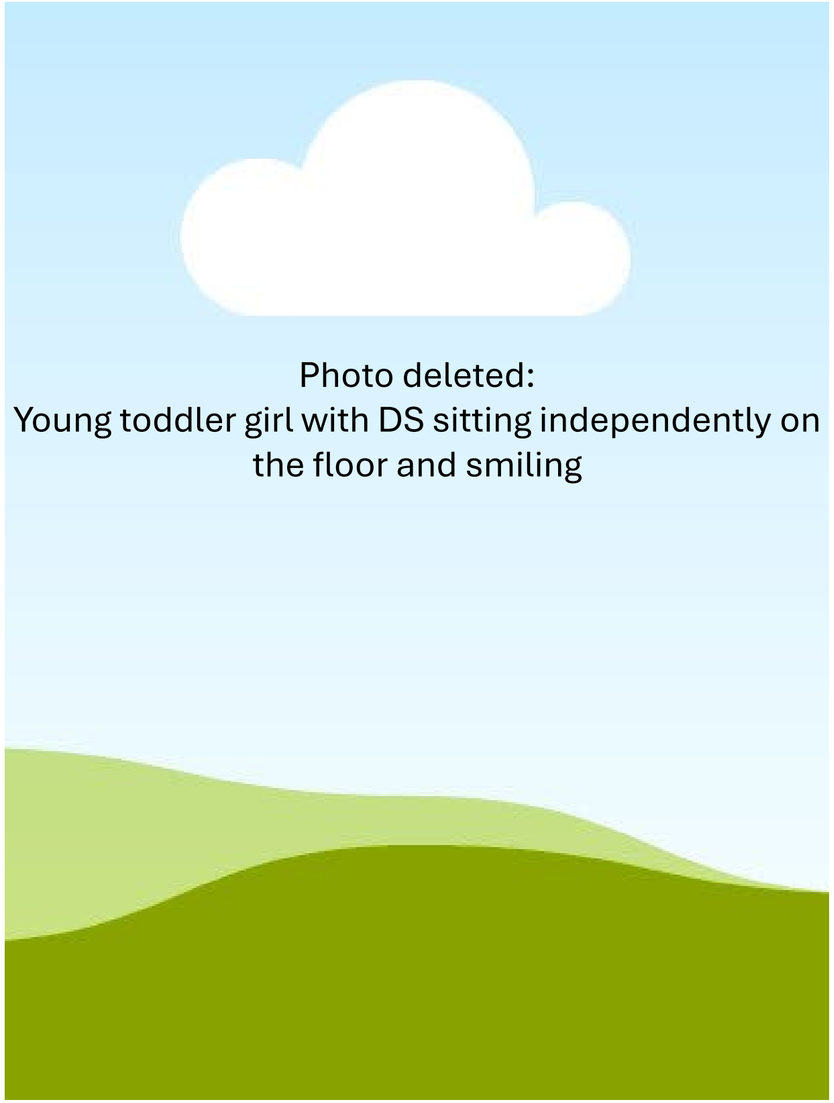


CVI in Down Syndrome

Hope

and

Urgency



CVI in Down Syndrome – Clinical Pearls

At Risk: all patients with Down syndrome

CVI Suspect: additional risk factors, including common aspects of neonatal life for babies with DS:

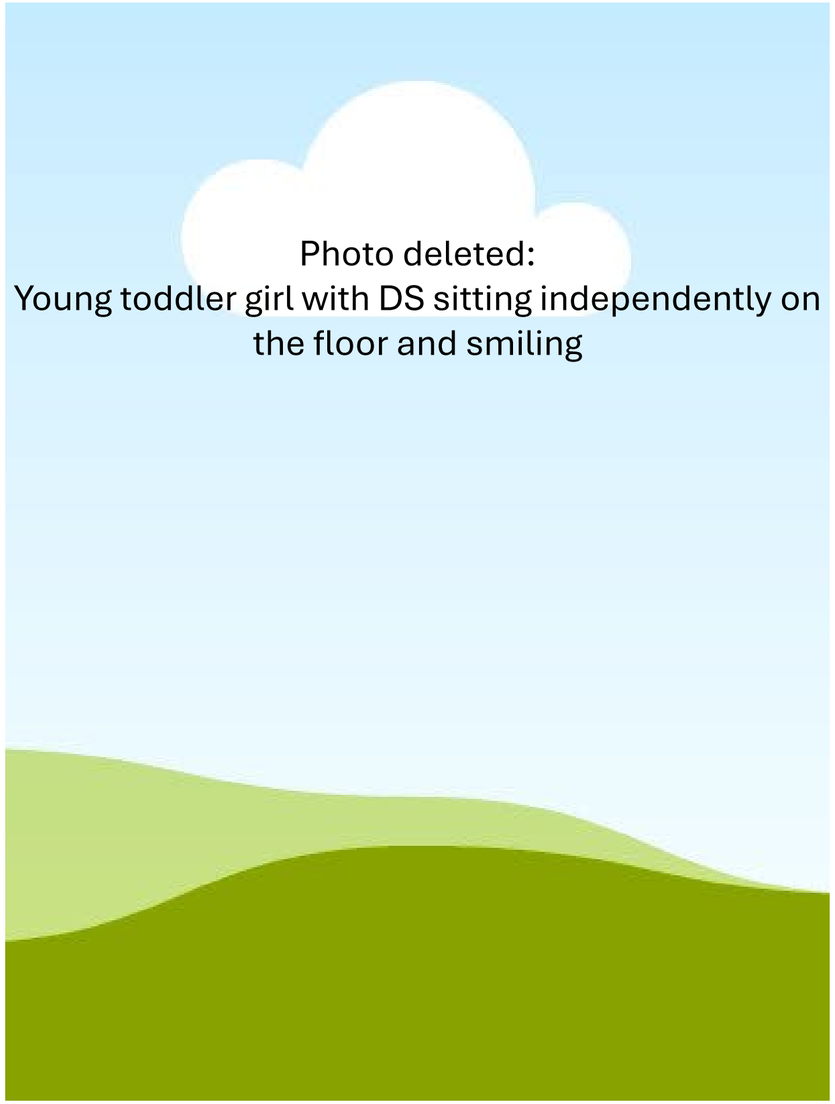
- hypoxia
- hypoglycemia
- hyperbilirubinemia

?basal ganglia lesions?

CVI Diagnosis: Atypical visual behaviors not explained by ocular conditions

- ophthalmologic exam
- Functional Visual Assessment (FVA) of higher order visual function

CVI Supports: No need to wait!



Boatwright E, Banihani R, Willems I, Lehman K, Mazel E, Mark H, Wong M, Vietzman S, Chandna A and Heidary G (2025) Cerebral/Cortical visual impairment (CVI) in Down syndrome: a case series. Front. Hum. Neurosci. 19:1563420.

Please Join Us!

DSMIG DS+CVI Workgroup

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Lisa Lind, TVI/COMS, MSW
Co-chairs
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DSMIG-USA® Down Syndrome Medical Interest Group
ANNUAL symposium
July 23-25 Orlando, Florida

Resources

NDSC Family Presentation
“More than Meets the Eye”

Supplementary Handout
“More than Meets the Eye”

Resources NDSC
“More than Meets the Eye”

Poster Presentation DSMIG:
“When ‘Mild ‘ is not Mild: Protective Bilingual Access in Down Syndrome with Dual Sensory Barriers”

Saturday, July 25
1:45-3:15 pm
Palm Beach

When to Suspect CVI, CVI and Down syndrome

CVI Screeners

Poster Viewing Area