Successfully Educating Students with ONH

how educators can make a difference from the start



"A diagnosis of optic nerve hypoplasia warrants neuroradiographic and endocrinologic testing for risk factors of delay and developmental assessments for early intervention planning."

Demographics



- At NMSBVI preschool campus 18 % of our population has a diagnosis of ONH
- Presently 32 confirmed cases under 3 years old – baby program
- 50% of the students in my classroom are diagnosed with ONH
- 1977 1.8 per 100,000
- 2006 10.9 per 100,000

Incidence at NMSBVI



- Cortical Visual Impairment (CVI)
 CVI due to Non-Accidental Head Trauma
 Optic Nerve Hypoplasia
- Coloboma
- Retinopathy of Prematurity
- Ocular Impairment
- Retinal Dystrophy



Ocular Impairment

Other

National Demographics

- Among children under 5 years of age
- prenatal Cataract is the leading cause of legal blindness, accounting for 16% of all cases.
- optic nerve atrophy (12% of all cases) and
- Retinopathy of Prematurity (9% of all cases)

(National Society to Prevent Blindness, 1980).

A study of children in schools for the blind in the United States revealed that 19% of 2553 children were cortically blind, and **12% had visual loss** from optic atrophy or optic nerve hypoplasia

(Steinkuller, Du, Gilbert, Foster, Collins, & Coats, 1999; cited in Gilbert & Foster, 2001).

What educators need to know about ONH

- Defining Characteristics
- Underdeveloped optic nerve
- **Clinical Associations:**
- Hypopituitarism dysfunction
- Developmental Delay
- Social Delay
- Motor Delay



Developmental specialists look for visual cues when identifying ONH in children -Small stature -Sensory issues

> "pallor" "small optic nerve" "Underdeveloped optic nerve"

When a child has a visual diagnosis of ONH, there are a host of other medical issues to test for.

- Brain evaluations and tests (CT, MRI)
- Hypopituitarism (pituitary malfunction)
- Growth Hormone (blood tests are required to measure growth hormone)
- 6:10 children with ONH do not make enough GH.
- Hypothyroid (TSH) "Thyroid levels should be checked when the diagnosis of ONH is made and at least every year after diagnosis."

- Sex hormones (Endrocinologist will perform a blood test. Tests should be performed when child is diagnosed or at less than 8 or 9 months of age)
- Cortisol production deficiency
- Low Blood Sugar "Lack of growth hormone, lack of cortisol or lack of both can cause a body's blood sugar level to be low.
- Low ADH (Diabetes Insipidus) dehydration and high sodium content

<u>www.chla.org</u> "Optic Nerve Hypoplasia: A Guide for Parents" *also available in Spanish

Strategies for Success : educating students with ONH



Educational Impact

• From – Optic Nerve Hypoplasia (presentation)

Julie Greenlee and Angela Howe

Stephen F Austin State University

The student will require some medical monitoring as well as educational assessment Depending on visual impairment increase or decrease font to meet needs of acuity and/or visual field

Will likely need an O&M evaluation

http://www.faculty.sfasu.edu



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Effective Teaching Strategies (general)

- Flexibility is key
- Adapt according to child's mood
- Discern causes of discomfort and stress
- Utilize quiet times of day for optimal learning
- Limit exposure to busy environments

- Be persistent
- Defined limits for behavioral challenges
- Consistency and communication for all team members
- Give the student coping strategies
- Keep calm
- Organize activities so the child is "in charge"

Specific Strategies



Increase sensory information according to child's cues

- Simple
- Single demand
- Familiar environment
- Reduced noise
- No peers
- 1 staff member



- Outside
- Windy, cold, sunny
- Noisy
- Pulling
- Walking
- Touching railings
- Ascending
- Instruction



Increasingly complex social situations and demands



Flexibility within instruction is vital because

- Sensory integration issues
- Discomfort brought on by incontinence, clothing, hunger, thirst, etc. . .
- Inability to deal with stress
- Irritability
- Fatigue/sleep issues
- Poor health

Keys to educational success for students with ONH

- Medical issues must be addressed before programming can be effective
- Advocates for the student must be able to explain "behaviors" based on their knowledge of the condition

• Think....





What is the role of the TVI/Early Interventionist?

- Provide medical information associated with ONH to both families and professionals
- Develop strategies with the team and ensure communication and consistency
- Debunk ONH stereotypes

Tools and Adaptations

• Object Permanence



Pre-literacy





Pre-braille





Assistive Technology

ZOOLA



FUN SOUNDS



MONSTER MELODY



"Feel Better" Menu

BEHAVIOR



J, 3 YEARS OLD



- Bilateral ONH
- Pituitary issues
- Sensory integration issues
- Difficulty dealing with stress
- Urinates frequently
- Poor appetite
- PICTURE OF JULIE NOW!

J, Now 5 Years



- Butterfly Protocol
 Choices
 Expectations
 Social success
- Active role during meals
- "Happy Plate"

Behavior Strategies

Allow student to participate in planning Process

Provide one on one time with an Adult before integration into group





Self-evaluation

Outcomes

Social Awareness



S, 3 years old

- Bilateral ONH
- Sensory integration
- Orally defensive
- Growth hormone
- Gross motor delays
- Language delays



E, 4 years

- "Extreme" Bilateral (NLP)
- Pituitary deficiencies
 (cortisol and thyroid)
- Gross and fine motor delays

Resources

- Dr Mark Borchert presentation in Albuquerque, 9/09 <u>www.chla.org</u> "ONH: a Guide for Parents"
- Septo-Optic Dysplasia/Optic Nerve Hypoplasia & Autism Spectrum disorders, Terese Pawletko
- From Optic Nerve Hypoplasia (presentation)
- Julie Greenlee and Angela Howe
- Stephen F Austin State University

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