



Visibility

Vol. 4, Issue 3, 2010

News and Research from **Envision Vision Rehabilitation Center**

“Excellence in Advocacy” Programming Set for Envision Conference 2010

“I like that the information is given in a multi-disciplinary fashion, and also that it is more advanced information than you can get at other conferences.”

- Kia Eldred, OD, FAAO

The program for Envision Conference 2010 has been set, and we hope you will join us in beautiful San Antonio September 22-25.

continued on page 16

**ENVISION
CONFERENCE**



The Case for Early Intervention

Richard L. Gaskill, EdD, LCPC, LCP

Neuroscientists are producing extraordinary new insights and knowledge about the process of brain development from infancy through adulthood. This knowledge is altering our approach to education, parenting and early childhood development, as well as intervention design, promising to improve our ability to support healthy human growth and development. The research also offers a compelling biological argument for prevention and early intervention services for most childhood disorders as the most effective and efficient service model.¹⁻³

Sophisticated research techniques, including advances in brain imaging, are informing us that a child’s brain organizes and develops neuronal patterns, “memory templates,” in a developmentally consistent and predictable

continued on next page



5 Guest Columns **13** Research Highlights **20** EVRC Update

 **ENVISION**
Vision Rehabilitation

sequence throughout childhood, beginning in utero. However, the human brain does not develop in a completely predetermined fashion so that all brains are pretty much identical in organization or function. To the contrary, the human brain is use dependent to guide development. Genetics directs only basic organization and function, allowing environmental experiences to uniquely configure the individual's brain organization. The intent of this interaction of genetics and experience is to organize the child's brain in a maximally efficient way for the world the child encounters from birth on. Much of this organizing takes place in the first four or five years of life, accounting for about 80 to 90 percent of the child's brain development.⁴⁻⁵

Although the brain continues to develop for many years, it never again develops so rapidly or effortlessly. In fact,

child development experts inform us that children learn 75 percent of their lifetime knowledge in the first couple years of life. This calculation is based on the total number of synaptic connections made in those first two years. Remarkably, we attend kindergarten, grade school and high school, and even graduate college, still attempting to amass the last 25 percent of our neural connections (knowledge). This last bit of organizing obviously takes considerably more effort and time than the first three quarters of brain organization, illustrating the importance of this early critical period for optimal learning. Since brain development is central to all child development, it becomes a critical variable to our ability to intervene on

behalf of children.⁴⁻⁵

If experience is vital to neural development,

what human interactions mediate this astonishing process?

The parent or caregiver-child relationship is central to this process. Child development experts have long understood relationships to be critical in the life of children, but brain science is just beginning to unravel the neurological underpinnings of these early relationships. Successful parenting, education, social relationships, emotional development, cognitive development and physical development are inextricably connected to these relationships. This is especially true of those relationships that feature caring, loving, patient, nurturing parents and caregivers. Children learn, heal and thrive in positive environments where they feel safe and receive considerable positive attention each day. Children regress, and even wither, in

hostile, negative, and punitive relational environments. Social relationships and interactions are clearly the social

mechanism of neurological programming of a child's developing brain. The human brain organizes itself in response to these early relational and environmental experiences, forming memory templates that will be used to judge all future experiences. These memory templates have a huge intellectual, emotional, social and developmental impact on the evolving brain, since the templates are the foundation of self-regulation, intellectual concepts, social relationships, and ultimately, more complicated and sophisticated thought processes. This critical interaction between nature and nurture continues to affect the child's developing brain most profoundly for many years. By understanding neuro-organizing principles and activities that stimulate or enhance development, teachers, parents and caretakers can effectively contribute to the healthy development of the children in their care.⁶⁻⁸

This new knowledge about brain development and the importance of adult child relationships mediating this process is stimulating a fresh appreciation for biologically and developmentally sensitive thought and practice surrounding early childhood development and early intervention strategies. It is now clear that we have a

very powerful window of opportunity to greatly support the development of our children in the first few years of their life, an opportunity that will never be as potent again. The old saying that "an ounce of prevention is worth a pound of cure"



high verbal families were more successful in school academically and socially, and showed better self-regulation (self-control). Not surprisingly, the children from the low verbalizing families struggled to keep up academically and to catch up

later. Further, by age 3, all children in the study were using their parents' words and sentences and mimicking their parents' grammatical patterns. Schools reported great difficulty improving the vocabulary, grammar and world views of children from the low verbalizing families. This strongly suggests that all the children in the study quickly learned and emulated their parents' vocabulary, language patterns and organization of thought in only three years. This is alarming considering that society spends only 5 percent of its financial investment in children by age 5, yet 95 percent of the neural development

has been established by that time.⁹⁻¹⁶

Clearly, our time, money and efforts are best invested in supporting early childhood relationships and early intervention for childhood difficulties. Efforts to deal with children's difficulties later in childhood is less successful and at significantly greater cost than early prevention or intervention. Social

continued on next page

policy research supports this position as well. Cost benefit studies have consistently reported that investing in early childhood prevention or intervention strategies during critical periods of brain development saves society \$17 for every dollar invested before age 5.^{7,11,17}

If we, as a society, want to solve many of the social, emotional and developmental problems found in society, we must begin to invest our energy and money in early development and early intervention. If we don't, we are destined to struggle to remediate social and developmental problems long after the opportune moment. Timing and relationships are everything.



Richard L. Gaskill, EdD, LCPC, LCP, is the Clinical Director and Deputy Director of the Sumner Mental Health Center in Wellington, Kansas, where he has developed child development classes, parenting classes, Child-Parent Relationship Training (Filial Therapy), Infant-Parent Relationship groups, attachment enhancement treatment groups, therapeutic alternative schools, therapeutic preschools, after school programs, and juvenile offender programs. Dr. Gaskill is also a Fellow of the Child Trauma Academy in Houston and an adjunct faculty member at Wichita State University where he teaches play therapy, child psychopathology, and supervises the play therapy practicum.



Approach to Low Vision and Early Intervention – A Case Study

Presenting Problem:

The student is a 5-year-old female with oculocutaneous albinism, congenital sensory nystagmus, and strabismus (esotropia). At 3 months of age, she was referred by the pediatrician for ophthalmologic evaluation and early intervention services. Glasses were prescribed at 3 years of age following surgery for strabismus. At that time, referrals were made for low vision rehabilitation evaluation and services of a vision teacher in the local school system. In the public school, she was placed in a preschool classroom with 9 other children. Distance visual demands in this setting were minimal based on her ability to move closer to instruction and that her primary learning modality was auditory. To address access to distant visual targets, she was trained to spot objects with an empty toilet paper roll. With this device, egocentric localization was addressed and developmental levels (seeing objects as a whole, not parts) were considered. After mastery of this task, transition to a low power (2.8X) monocular was made.



continued on next page

Rebecca B. Coakley,
MA, CLVT



**Rebecca B. Coakley,
MA, CLVT**

Director and Pediatric Low Vision Education Specialist,
Children's Vision Rehabilitation Program,
West Virginia University Eye Institute

“Approaching the needs of the low vision student as ‘always changing’ and responding accordingly is essential.”

References

1. Barfield, S. *Best Practices in early childhood mental health programs for preschool children*. A report to the Kansas Department of Social and Rehabilitation Services, Topeka: Division of Health Care Policy, State of Kansas, 2004.
2. Barfield, S., Gaskill, R., Dobson, C., & Perry, B. *Examining the effects of the Neurosequential Model of Therapeutics (NMT) with Filial Therapy in a preschool setting: implications for work with children with serious emotional disturbance*. 2006; in preparation.
3. van der Kolk, B. Clinical implications of neuroscience research in PTSD. *Annals of the New York Academy of Science*, 2006; 1071 (IV), 277-293.
4. Hawley, T. *Starting smart: how early experiences affect brain development*. Ounce of Prevention Fund & Zero to Three, publications. Chicago, Illinois, 2000.
5. MacLean, P.D. *The triune brain in evolution: Role in paleocerebral functioning*. New York: Plenum Press, 1990.
6. Perry, B.D. Child maltreatment: the role of abuse and neglect in developmental psychopathology. In Theodor P. Beauchaine & Stephen P. Hinshaw, (Eds) *Textbook of Child and Adolescent Psychopathology*. New York: Wiley, 2008: 93-128.
7. Perry, B.D. The neurobiology of childhood maltreatment: the neurodevelopmental cost of adverse childhood events. In K. Franey, R. Geffner, & R. Falconer, Eds., *The cost of maltreatment; who pays? we all do*. San Diego: Family Violence and Sexual Assault Institute, 2000.
8. Perry, B.D. The neurodevelopmental impact of violence in childhood. In Schetky, D. & Benedek, E., Eds., *Textbook of child and adolescent forensic psychiatry*. Washington, D.C.: American Psychiatric Press Inc, 2001.
9. Bratton, S. & Ray, D. What research shows about play therapy. *International Journal of Play Therapy*. 200; 9(1), 47-88.
10. Elkind, D. *The commercialization of play*. Paper presented at the Play and Time Lego Conference. Copenhagen, Denmark, 2003.
11. Gaskill, R. *Neurosequential model of therapeutics: protocol for core elements of the therapeutic program*. Unpublished manuscript, 2007. Available from Child Trauma Academy, www.ChildTrauma.org.
12. Miranda, L., Arthur, A., Mahoney, O., & Perry, B.D. The art of healing: The healing arts project, early childhood connection: *Journal of Music and Movement-Based Learning*. 1998; 4(4), 35-40.
13. Miranda, L., Schilick, S. Dobson, C., Hogan, L., & Perry, B.D. *The positive developmental effects of brief music and movement program at a public preschool*. A pilot project abstract. 1999. Available at www.childtrauma.org/ctaServices/neigh_artsasp.
14. Perry, B.D. & Szalavitz, M. *The boy who was raised as a dog: and other stories from a child psychiatrist's notebook*. New York: Basic Books, 2006.
15. Perry, B.D., Conroy, L. & Ravitz. *Persisting psychophysiological effects of traumatic stress: “the memory of states”*. Child Trauma Academy, 1991. Retrieved June 12, 2008 from: http://www.childtrauma.org.
16. Perry, B.D. & Pollard, R. Homeostasis, stress, trauma and adaptation: a neurodevelopmental view of childhood trauma. *Child and Adolescent Psychiatric Clinics of North America*, 1998; 7(1), 33-51.
17. Perry, B. D. Applying principles of neurodevelopment to clinical work with maltreated and traumatized children: the Neurosequential Model of Therapeutics. In N.B. Webb (Ed), *Working with traumatized youth in child welfare*. New York: Guilford Press, 2006.

Training in the use of the device was integrated in the classroom setting, creating an opportunity to access information at a distance. Despite the potential social stigma associated with device use, the child and her peers accepted the device without hesitation.¹

In kindergarten, visual demands in the classroom setting changed. The opportunity to move freely in the classroom decreased. The student was expected to obtain visual information at a distance of 5-10 feet. Visual instruction overshadowed auditory opportunities for learning. Computers were integrated into the educational environment.

To address light sensitivity, dark tinted contact lenses were substituted for glasses 80 percent of the time resulting in improved best corrected visual acuity (BCVA), contrast and comfort. A reading stand was added to facilitate relative magnification.¹

Areas of visual function affected are central visual acuity (distance and near), light sensitivity, depth perception, contrast sensitivity threshold, and orientation and mobility.

BCVA: (Distance)
 OD 20/300
 OS 20/300
 OU 20/200 (glasses) 20/125 (contacts-dark tint)

(Near)
 OU 20/125 (40/2.5M)
 OU 20/63 (1.25M) at 15cm

Color vision: within normal limits

Confrontation visual field: full

Depth perception: absent

Contrast sensitivity threshold: 10% (slightly elevated)¹

Practical Considerations

Additional device selection criteria:

Cognitive ability

- Are there cognitive or behavioral considerations that may preclude the use of the device?
- Can the child view in parts (power of magnification and field size)?
- Egocentric localization

Physical ability

- Are there physical limitations that would prohibit the child from using the device (i.e. cerebral palsy, paralysis)?

Environmental need

- Does the child's educational environment provide an opportunity for use of the devices?
- Does the child's home environment provide an opportunity for the use of the devices?

Medical / Visual Function Considerations

Diagnosis	Definition	Onset	Progressive	Vision Range (Best Corrected)
Albinism	Inherited lack of pigment in the skin and eyes	Birth	No	20/40 - 5/200
Nystagmus	Involuntary rhythmic movement of the eyes, usually associated with damage to the anterior vision system	2-3 months	Often slows with age	Depends on disease

Vision Function Deficits

Diagnosis	Blur	Glare/ Light Sensitivity	Adaptation to Dark	Loss of Contrast	Visual Field Defects	Nystagmus	Color Vision	Other	Mobility
Albinism	++	++++	-	-	-	+ often less prominent with age	Normal	Poor absent depth perception, often astigmatism nearsightedness	+ in bright light
Nystagmus	++	+/-	+/-	+/-	+/-	++++ Children often adopt a head turn or gaze to slow the eye movements and improve vision	Normal	Usually caused by poor vision and not the cause of poor vision	-

continued on next page

Educational Considerations

Assessment	Does a referral need to be made?	Justification for Assessment
Technology Assessment	<input type="radio"/> Yes <input type="radio"/> No	Acuity (near and distance), glare
Low Vision Assessment	<input type="radio"/> Yes <input type="radio"/> No	Acuity, depth perception, contrast, light sensitivity, refractive error
Orientation and Mobility Assessment	<input type="radio"/> Yes <input type="radio"/> No	Depth perception, acuity
Functional Vision Assessment	<input type="radio"/> Yes <input type="radio"/> No	Diagnosis, acuity, depth perception, light sensitivity
Occupational Therapy	<input type="radio"/> Yes <input type="radio"/> No	

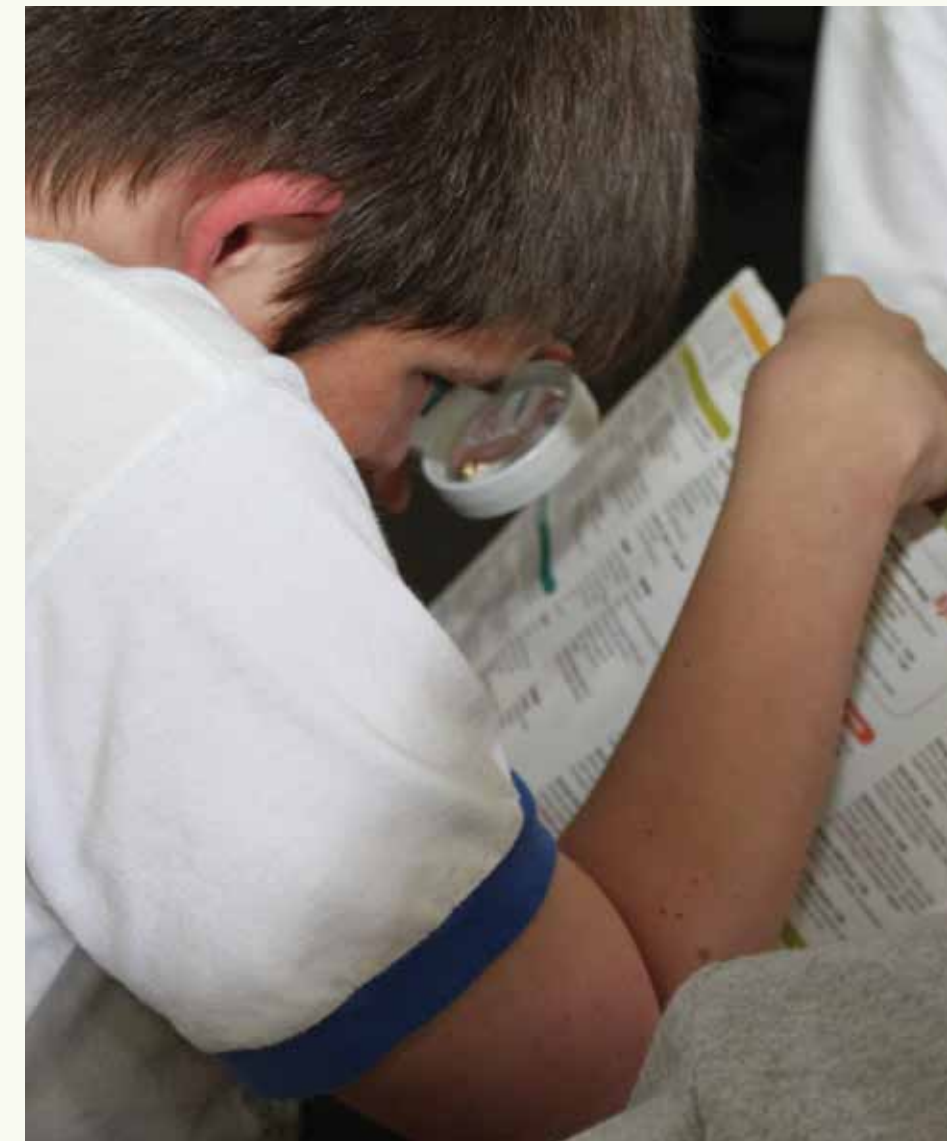
Educational Recommendations

1. Due to light sensitivity, the student should be seated with her back toward the window. A hat, visor, and/or sunglasses should be worn outdoors.
2. The student should be allowed to hold materials as close as needed to maximize visual function (relative magnification).
3. At distance, the student should use her monocular to view targets, especially during instruction. Opportunities should be made each day to demonstrate the need for the devices. For example, move the child further from instruction to encourage device use (10 ft).
4. Bold lined paper should be made available when the ability to see targets at reduced contrast is impaired. Avoid light-colored crayons and print.
5. The student should be permitted to move freely around the room to gain access to distant information when not using devices.
6. An orientation and mobility assessment should be considered due to the combination of reduced VA, absent depth perception and light sensitivity.
7. An assistive technology assessment should be initiated to address computer use and distance and near tasks.
8. A portable slant board should be used to enhance relative magnification, improve posture, and reduce fatigue.
9. Ambient classroom light should be reduced by extinguishing some overhead lighting, preferential seating with back to window, and non-optical devices (i.e. sun filter, hats, visor, and antireflective paper).²

Future Considerations

Children with low vision from albinism respond well to modifications, magnification and assistive technology. As classroom visual demands increase, technology which provides both near and distance magnification should be considered.² Controlling ambient light is the most important classroom modification. Yearly ophthalmologic exams to address refractive error and health of the eye are important.

In conclusion, the approach to early intervention and low vision rehabilitation requires knowledge of the eye condition, educational demands, functional visual deficits, long-term prognosis, and educational support services. A collaborative approach that includes the students, parents, medical and educational providers enhances the outcome. Approaching the needs of the low vision student as “always changing” and responding accordingly is essential.



Many children with low vision can benefit from magnification and assistive technology.

References

1. Medical, refractive interventions: Terry Schwartz, MD. Pediatric Ophthalmology, WVU Eye Institute, Morgantown, WV.
2. Corn, AL. Optical Aids in the Classroom. *Education of the Visually Handicapped* 1980 12 (4), 114-21.

Rebecca B. Coakley, MA, CLVT, is Director and Pediatric Low Vision Education Specialist for the Children’s Vision Rehabilitation Program, West Virginia University Eye Institute. Rebecca Coakley graduated from Marshall University with a Bachelor’s degree in Education, specializing in Elementary and Mentally Impaired, a Master’s in Administration from West Virginia Graduate College, and Blind and Visually Impaired Certification from the University of Virginia. She is a certified Low Vision Therapist through ACVREP. Rebecca has worked in the field since 1989 and presents on the topic of low vision nationwide. Rebecca has taught courses for Southwest Missouri State University and is currently an adjunct professor at Marshall University Graduate College and West Virginia University.

Case Report: Contact Lenses for Infants with High Refractive Error: Evidence of the Sooner the Better! Part II



William L. Park, OD, FAAO

Private practice, LLC

Past Director of Low Vision Services, Lions Research & Rehabilitation Center, Wilmer Eye Institute-Johns Hopkins University

Recently, The Infant Aphakia Treatment Study deliberated the use of contact lenses and intraocular lenses (IOLs) for the optical correction of unilateral aphakia during infancy. In a randomized, multicenter (12 sites) clinical trial, 114 infants with unilateral congenital cataracts were assigned to undergo cataract surgery with or without IOL implantation. Children randomized to IOL treatment had their residual refractive error corrected with spectacles versus children randomized to no IOL treatment and had their aphakia treated with a contact lens.¹

Grating acuity at 12 months of age and HOTV visual acuity at 4 years of age was measured. Enrollment began December 23, 2004 and was completed January 16, 2009. The median age at the time of cataract surgery was 1.8 months. The study found that eyes with cataracts had shorter axial lengths and steeper corneas on average than the fellow eyes. The optimal optical treatment of aphakia in infants is unknown. The Infant Aphakia Treatment Study was designed to provide empirical evidence of whether optical treatment with an IOL or a contact lens after unilateral cataract surgery during infancy is associated with a better visual outcome.

Opinions vary about when cataract surgery should be performed on an infant. Cataract surgery may need to be performed as soon as possible to ensure that media is clear enough to allow normal development of the baby's visual system. Some experts say the optimal time to intervene and remove a visually significant congenital cataract from an infant's eye is between the age of 6 weeks and 3 months.¹

The following cases demonstrate the use of contact lenses to obtain maximum development of visual acuity and visual perception. This involved examination and identification of the benefits of contact lenses on these children based on observation and feedback of peers, family and teachers of the visually impaired.

Case Study 1, LD

LD, a full-term baby, developed bilateral congenital cataracts 12 weeks following birth, with symptoms of cloudy lenses in each eye, intermittent nystagmus, alternating esotropia and rolling of the eyes upward. Surgery was performed at 15 weeks on the right eye and



Case Study 1, LD

22 weeks on the left eye by a pediatric ophthalmologist.

LD was seen for a second opinion for various reasons and ultimately fit with Kontur contact lenses with a prescription of OD +26.00, OS +29.00 with a 7.20 mm curvature and 13 mm diameter (increased from a diameter of 12mm based on follow-up) in both eyes. Visual acuity was 13 mm ball at 17 feet. All gross and fine motor skills along with visual function are normal based on multiple follow-up visits over 20 months.

Case Study 2, MD

MD was a full-term baby, born 17½ months after LD, with congenital bilateral cataracts like her brother. Contact lens fitting was evaluated and completed in the exam room at 51 days old.

Bilateral cataracts were noted by the parents and evaluated ophthalmologically with cataract extraction performed in the left eye. A contact lens trial was performed in the exam room, on the floor and countertop.

Based on that trial, MD was fitted with 7.20 base curve, +17.50 D in a 12 mm lens. The lens demonstrated a well-centered lens with excellent centration, good movement and uniform tear exchange based on observation with hand-held biomicroscopy with and without flourossoft. Insertion, toler-

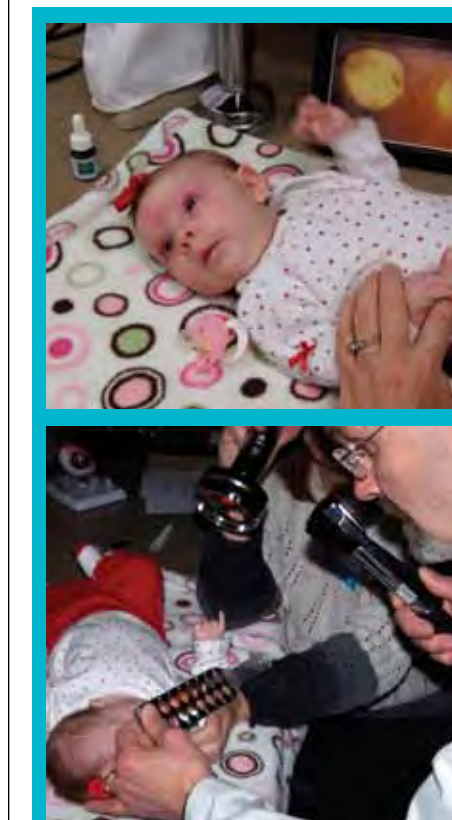
ance of wear and response to stimuli of various size objects was excellent. MD is currently being monitored for her contact lenses concerning visual function and physiologically for anterior segment health.

Case 3, JR: A different point in time and a lesson in the "sooner the better."

JR was diagnosed at birth (1967) with mild Cerebral Palsy, congenital nystagmus, ROP, glaucoma, cataracts and ultimately had a bilateral lensectomy resulting in aphakia of both eyes. Review of systems was significant for a recent history of Lyme's Disease and Fibromyalgia.

JR was first seen at 42 years of age and was unemployed at that time due to vision and health issues (Lyme's Disease). JR presented with a visual acuity of OD 20/160 OS 20/560, with a visual field of 110 degrees (Goldmann). Visual acuity with the bioptic expanded field telescopic system prescribed in his

continued on next page



Case Study 2, MD

Mark S. Borchert, MD and
Pamela Garcia-Filion, MPH



Case Study 3, JR

months later, visual acuity was OD 20/30+2, OS 20/200 with an improvement in his visual field to 125 degrees. JR was informed that for the first time in his life, he was legal to drive based on state law. JR's case illustrates the impact of appropriate prescription and low vision rehabilitation intervention at an early age, versus vision replacement skills only, which

youth was 20/40 using his right eye. This device gave support for distance and intermediate visual tasks, along with assisting him in safe travel and identifying appropriate bus transportation.

The patient was counseled at the initial examination on consideration of contact lenses for maximum visual performance, due to the aberration and degradation of acuity in glasses (an

alternative never offered).

JR was ultimately fit with soft contact lenses following the initial evaluation and a subsequent five-hour clinical/subjective environmental trial. The final soft contact lens parameters were OD +16.00, OS +18.50 lenses (8.90 base curve, 15.0 diameter OU).

At the conclusion of the final visit approximately three

were all that was available to him during his tenure at a school for the blind.

REFERENCES:

1. Lambert SR, Buckley EG, Drews-Botsch C, et al. The infant aphakia treatment study: design and clinical measures at enrollment. *Arch Ophthalmol* 2010; 128(1): 21-27. 13.
2. Park WL, Park JM, Schwartz TL, Coakley B, Odom JV. Contact Lenses as an Adjunct of Rehabilitation in the Children's Vision Rehabilitation Project (CVRP). *Invest. Ophthalmol. Vis Sci.* 2007 49:E-Abstract 3158.
3. Nowakowski RW. Contact lens applications in low vision rehabilitation. *Primary Low Vision Care*. Norwalk; Appelton & Lange, 1994; 207-213.
4. Wechsler S. Visual acuity in hard and soft contact lens wearers. A comparison. *J Am Optom Assoc*; 1978; 49(3): 251-56.
5. Hensil J, Gurwood AS. Understanding Nystagmus. *Optometry* 2000;71(7):439-48.

William L. Park, OD, FAAO

Dr. Park is in private practice in Wichita, KS. Dr. Park is committed to outreach efforts in stemming the epidemic of diabetes. He works exclusively with patients referred for low vision evaluation, low vision rehabilitation and neurological vision loss. He is a past Director of Low Vision Services, Lions Research & Rehabilitation Center, Wilmer Eye Institute-Johns Hopkins University. Dr. Park can be reached at William L. Park, OD, LLC, www.parklowvision.com, 610 N. Main, Suite 201 Wichita, KS 67203, (316) 440-1690 or drpark@parklowvision.com.

Optic Nerve Hypoplasia: An Epidemic Birth Defect

Mark S. Borchert, MD and Pamela Garcia-Filion, MPH

Overview of ONH

The birth defect known as optic nerve hypoplasia (ONH), characterized by an underdeveloped optic nerve, has been recognized as an increasingly frequent problem in children.¹⁻³ Prior to 1970, ONH was a phenomenon.¹ In the 30 years following, the prevalence of ONH increased six-fold to the current estimate of 1 per 10,000 children.^{3,4} In the United States, ONH was recently reported as the foremost ocular cause of blindness and visual impairment in young children.⁵

ONH as a diagnosis has been misunderstood for decades owing to its association with "septo-optic dysplasia" (SOD). Since the first description of ONH and subsequent characterization of SOD, research has made tremendous progress in understanding the clinical significance of ONH. It is now clear that ONH is a pervasive disease of child neurodevelopment associated with overall miswiring of the brain; visual impairment is merely the central feature. Despite the rapid rise in prevalence, the etiology of ONH remains largely unknown.

The underdeveloped optic nerve in ONH is caused by an interruption in the migration and connections of nerve fibers within the optic tract in early gestation. Approximately 80 percent of children with ONH are bilaterally affected.^{6,7} Visual impairment may range from no light perception to near normal vision, with some association with the size of the optic nerve. ONH is not a degenerative disease; in fact, a majority of children with ONH will experience some improvement in visual function by 5 years of age.⁷ While the reasoning behind improvement is unclear, it is thought to be attributable to improved optic nerve function due to normal myelination in early life.

Visual impairment is rarely an isolated feature of ONH. Evidence from prospective studies demonstrates that all children diagnosed

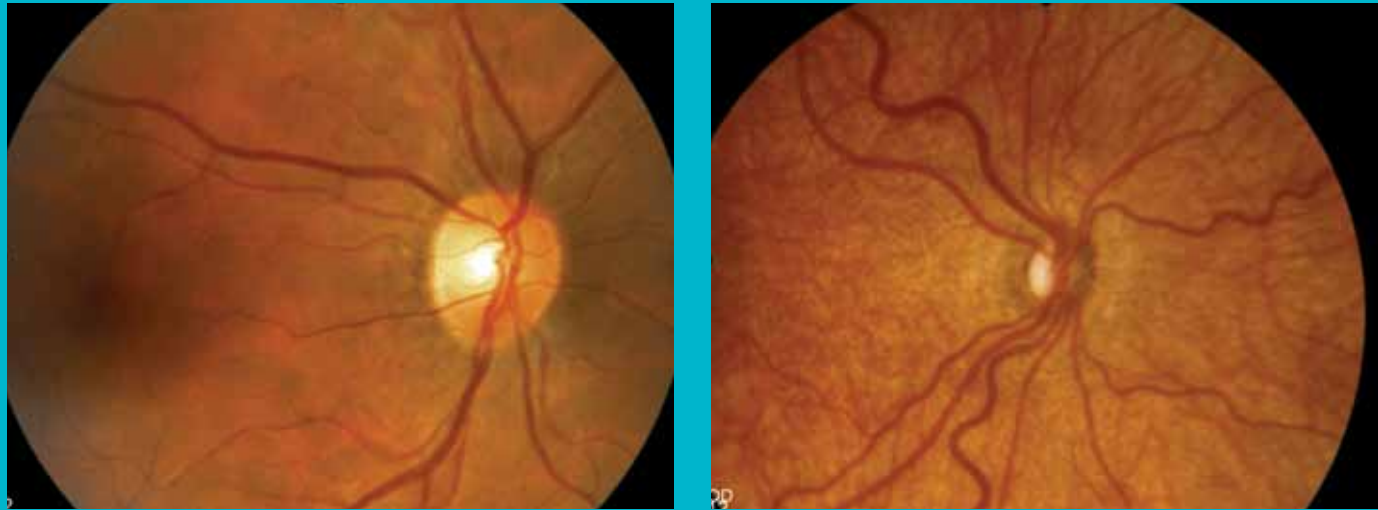


Mark S. Borchert, MD

Director of the Eye Birth Defects Institute and Eye Technology Institute, Vision Center at Childrens Hospital Los Angeles where he is head of the Division of Ophthalmology

Associate Professor of Clinical Ophthalmology and Neurology at the Keck School of Medicine of the University of Southern California

continued on next page



with ONH face profound risk of co-morbidities involving the central nervous system, regardless of the presence of brain malformations. Endocrine dysfunction is the most common diagnosis associated with ONH, affecting 75-80 percent of children.^{6, 8} Notably, the presence of endocrine dysfunction is unrelated to laterality of disease or the presence of a brain malformation. Overall developmental delay affects 71 percent of children with ONH. Delays in motor skills are the most common (75 percent) and communication skills the least common (42 percent). Risk factors include a small corpus callosum and hypothyroidism but not absence of the septum pellucidum. Unilateral or mild cases of ONH are not protected from developmental delay.⁶ Autism has been found in 31-43 percent of children with ONH.^{9, 10}

Most of the clinical problems associated with ONH are

attributable to a dysfunctional hypothalamus. Other manifestations of hypothalamic dysfunction commonly seen in children with ONH include poor temperature regulation, food and/or water seeking compulsion, and abnormal sleep-wake cycles.¹¹

ONH Program

The Vision Center at CHLA is home to a program dedicated to serving children with ONH. Since 1992, the ONH program led by Dr. Mark Borchert has served as a primary referral center for patients with ONH nationwide. Due to the complexity of the syndrome of ONH, clinical care for a child with ONH is multi-disciplinary, involving ophthalmology, endocrinology, neurology, neuropsychology and early intervention programs. This team approach allows for a unique ability to research all aspects of ONH. Research activities have expanded from a single prospective study

to a research registry and seven specialized studies. The purpose of the ONH program is to disseminate information to clinicians and families so that they are better able to care for these very special children.

Prospective research findings from the ONH program collectively led to the development of recommendations for the clinical management of children with ONH.² An ONH research registry was established to monitor the clinical characteristics and outcomes associated with ONH through childhood and adolescence. In addition to studying the clinical correlates of adverse outcomes, registry information supports the development of specialized studies. Currently, studies are underway to examine autism associated with ONH, early GH replacement therapy on growth, obesity and development, and sleep disturbances in ONH and treatment with melatonin.

Research into the epidemi-

ology of ONH is a significant focus of the ONH program. As part of the research registry, a standard prenatal questionnaire is performed with mothers of participants. A recent study confirmed young maternal age and primiparity as risk factors, refuted many risk factors such as alcohol, recreational drug use and viral infection, and introduced potentially significant risk factors. Gestational vaginal bleeding, preterm labor, low weight gain and weight loss were common.⁶ Follow-up research is focusing on the role of nutrition as a contributing factor to the development of ONH.

Epidemiologic research was expanded in 2004 with the launching of a national online disease distribution study to investigate the geographic distribution of ONH in the United States. The study aims to determine if unique distribution patterns exist and the association with population and environmental characteristics. Families that have a child with ONH are notified of the survey's availability either through a service provider for visually impaired children or various web resources for families with ONH. The brief survey asks for the child's birth season/year, race/ethnicity and the residential address of the mother during the three months prior to conception and during the first and second trimesters. Participation is voluntary and data are

protected by a NIH Certificate of Confidentiality. Geographic information has been received for 1500 cases of ONH thus far, dating as far back as 1956.

Findings from the national disease distribution study will advance ONH research by providing information about the geographic distribution of ONH across populations, and may offer direction for subsequent investigations into disease risk

factors. This survey study is ongoing, with quarterly reminders to service providers about the survey's availability. The survey is available on the Facebook fan page for the ONH program or at www.onesmallvoicefoundation.org. Service providers that would like to be added to our listserv should send their contact information to Pamela G. Filion at pgarciafilion@chla.usc.edu.

Mark S. Borchert, MD, is director of the Eye Birth Defects Institute and Eye Technology Institute in the Vision Center at Childrens Hospital Los Angeles where he is head of the Division of Ophthalmology. Dr. Borchert is also an Associate Professor of Clinical Ophthalmology and Neurology at the Keck School of Medicine of the University of Southern California. He directs the world's largest study of optic nerve hypoplasia, now the single leading cause of blindness in infants in the United States and Europe.

REFERENCES:

1. Acers TE. Optic nerve hypoplasia: septo-optic-pituitary dysplasia syndrome. *Trans Am Ophthalmol Soc* 1981;79:425-57.
2. Borchert M, Garcia-Filion P. The syndrome of optic nerve hypoplasia. *Curr Neurol Neurosci Rep* 2008;8(5):395-403.
3. Jan J, Robinson G, Kinnis C, MacLeod P. Blindness due to optic-nerve atrophy and hypoplasia in children: an epidemiological study (1944-1974). *Dev Med Child Neurol* 1977;19(3):353-63.
4. Patel L, McNally R, Harrison E, Lloyd I, Clayton P. Geographical distribution of optic nerve hypoplasia and septo-optic dysplasia in Northwest England. *J Pediatr* 2006;148(1):85-8.
5. Hatton D, Schwietz E, Boyer B, Rychwalski P. Babies Count: the national registry for children with visual impairments, birth to 3 years. *J AAPOS* 2007;11(4):351-5.
6. Garcia-Filion P, Epport K, Nelson M, Azen C, Geffner ME, Fink C, et al. Neuroradiographic, endocrinologic, and ophthalmic correlates of adverse developmental outcomes in children with optic nerve hypoplasia: a prospective study. *Pediatrics* 2008;121(3):e653-9.
7. McCulloch DL, Garcia-Filion P, Fink C, Chaplin CA, Borchert MS. Clinical electrophysiology and visual outcome in optic nerve hypoplasia (ONH). *Br J Ophthalmol* 2009.
8. Ahmad T, Garcia-Filion P, Borchert M, Kaufman F, Burkett L, Geffner M. Endocrinological and auxological abnormalities in young children with optic nerve hypoplasia: a prospective study. *J Pediatr* 2006;148(1):78-84.
9. Ek U, Fernell E, Jacobson L. Cognitive and behavioural characteristics in blind children with bilateral optic nerve hypoplasia. *Acta Paediatr* 2005;94(10):1421-6.
10. Parr JR, Dale NJ, Shaffer LM, Salt AT. Social communication difficulties and autism spectrum disorder in young children with optic nerve hypoplasia and/or septo-optic dysplasia. *Dev Med Child Neurol*. 2010 Mar 29 [Epub ahead of print]
11. Rivkees SA, Fink C., Nelson M., Borchert, M. Prevalence and risk factors for disrupted circadian rhythmicity in children with optic nerve hypoplasia. *Br J Ophthalmol* 2010; In press.

Program Topics and Session Highlights

OPTICAL DEVICES AND PRESCRIBING

Why Contact Lenses are Important in Your Low Vision Rehabilitation Practice

William L. Park, OD, FAAO;
Joanne Park, COA

This Grand Rounds-format session discusses indications and rationale for specific types of lenses for high refractive error and ocular pathology for BCVA. Visual function and quality of life issues are conveyed through outcome measurements of 20+ years with ages of 59 days old to 60+ years and prescriptions to 53D.

LOW VISION AND DRIVING

Fitting Bioptic Telescopes for Driving

Dawn DeCarlo, OD, FAAO

This course will provide attendees with an overview of the bioptic

driving literature as well as an understanding of the strengths and limitations of different types of bioptic telescopes. The main focus of the presentation will be proper patient and telescope selection and the fitting and dispensing process.

TRAUMATIC BRAIN INJURY

The School of Hard Knocks – Recognizing and Rehabilitating the Soft Signs of TBI

Joseph Hallak, OD, PhD;
Joseph Bacotti, MD, FACS
Stage 3 Traumatic or Acquired Brain Injury presents with soft and often elusive signs that are difficult to sort out and recognize, let alone rehabilitate. We will consider how their effect impacts various essential functions and hinders societal reintegration and functioning. We will discuss the goal of a successful rehabilitation that is to address these issues of functioning and reintegration.

PROFESSIONAL ISSUES

A Look Beyond the Medical – Fight for Your Client's Rights

Jennifer Elgin, OT
Looking beyond the medical side of vision impairment can greatly benefit our clients. Federal law IDEA requires that school systems make accommodations for students with any impairment that could interfere with success in the classroom. This includes students with vision impairment. Many eye care professionals are focused on the eye health

and treatment of the conditions and may be unaware of options for their patients beyond the medical. However, the eye care professional is the most obvious source for the process to begin. This presentation will discuss the federal laws for children with disabilities (specifically visual impairment) and give professionals information to help their clients become advocates for their rights.

PEDIATRICS, EARLY INTERVENTION

Through the Eyes of a Child: Working with Youngsters who are Visually Impaired

Sarah Hinkley, OD, FCOVD

This clinically relevant course will introduce professionals from any rehabilitative discipline to the current cross-over and expansion associated with the term “rehabilitation.” It will discuss the challenges associated with rehabilitating pediatric patients who are visually impaired and practical clinical strategies for maximizing positive impact on this patient population.

CLINICAL PRACTICE APPLICATIONS

Managing the Patient with Unilateral Neglect and Low Vision: Challenges and Strategies for Vision Rehabilitation

Lauren Nisbet, OT; Mary Lou Jackson, MD – Ophthalmology

This presentation educates vision rehabilitation professionals about the specific challenges, functional

effects, and evidence-based rehabilitation strategies when working with patients with visual field neglect. Clinical cases will be presented.

Other topics include:

- Psychosocial Issues in Vision Loss
- Disease Etiology
- Multi-Disciplinary Models of Low Vision Rehabilitation
- Adding Low Vision Rehabilitation to Your Practice

The Envision Conference website has been updated to include the **Envision Conference 2010** clinical education and research sessions schedule. Visit the Sessions & Events section at www.envisionconference.org. There, you will find the times of each clinical and research session. Click on the links to view session descriptions and speaker bios. If you have any questions about workshops, clinical education or research sessions at **Envision Conference 2010**, email Michael Epp at michael.epp@envisionus.com.



→ *“The close co-working between people with different professional backgrounds that exists here is extremely good. I think we can really make sure our research goes forward to best benefit people with low vision.”*
-Michael Crossland, PhD,
MCOptom, FAAO

Envision Conference 2010 Research Sessions Highlights

PERCEPTUAL FILLING-IN

Walter Wittich, PhD, Integrated Program in Neuroscience, McGill University, Research Coordinator, MAB-Mackay Rehabilitation Center, Montreal, Canada

PREFERRED RETINAL LOCUS

Michael Crossland, PhD, MCOptom, FAAO, Specialist Optometrist, Moorfields Eye Hospital NHS Foundation Trust Research Fellow, UCL Institute of Ophthalmology, London

LOW VISION RESEARCH NETWORK (LOVRNET)

Judith Goldstein, OD, FAAO, Chief of Low Vision Clinical Services, Wilmer Eye Institute at Johns Hopkins University

RESEARCH PANEL ON EMPLOYMENT

Deborah Gold, PhD, Director, Research, Canadian National Institute for the Blind, Toronto, Canada

RETINITIS PIGMENTOSA: STILL A CHALLENGE

Olga Overbury, PhD, School of Optometry, University of Montreal, Montreal, Quebec

RESEARCH AND READING: LOW VISION REHABILITATION IMPLICATIONS

Donald Fletcher, MD, Smith-Kettlewell Eye Research Institute, San Francisco, CA; California Pacific Medical Center Department of Ophthalmology, San Francisco, CA; Helen Keller Foundation for Research and Education, Birmingham, AL; University of Kansas Department of Ophthalmology, Kansas City, KS; Medical Director, Envision Vision Rehabilitation Center, Wichita, KS

QUALITY OF LIFE INDICATORS

Robert Massof, PhD, Wilmer Eye Institute, Johns Hopkins University School of Medicine

MOBILITY & SAFETY

Shirin E. Hassan, BAppSc(Optom), PhD, Assistant Professor, Indiana University School of Optometry

To view the conference programming and to register, visit the conference website at www.envisionconference.org. Please contact Michael Epp, Director of Outreach & Continuing Education, with questions about the Envision Conference at (316) 440-1515 or email michael.epp@envionus.com.

The research program at Envision Conference is convened by the Envision Conference 2010 Research Abstract Review Board.

- **Laura Dreer, PhD**, Assistant Professor of Ophthalmology, University of Alabama at Birmingham, Callahan Eye Foundation Hospital
- **Shirin E. Hassan, BAppSc(Optom), PhD**, Assistant Professor, Indiana University School of Optometry
- **Robert Massof, PhD**, Lions Vision Research and Rehabilitation Center, Wilmer Eye Institute, Johns Hopkins University School of Medicine
- **Ronald Schuchard, PhD**, Research Career Scientist, Atlanta VA R&D Service, Associate Professor of Neurology, Emory University
- **George T. Timberlake, PhD**, Professor, Department of Ophthalmology, University of Kansas Medical Center

Make the Envision Conference and San Antonio River Walk Your Destination this September



“To see a beautiful venue like this and a conference that focuses so much on collaboration of care – it’s an exciting conference!” Paul H. Davis, MD

Located in the heart of Texas, San Antonio has been called “The Cultural Gateway to the American Southwest.” As the oldest city in the state, founded in 1781 as a Spanish settlement, San Antonio’s atmosphere is unlike that of any other city in Texas. The biggest

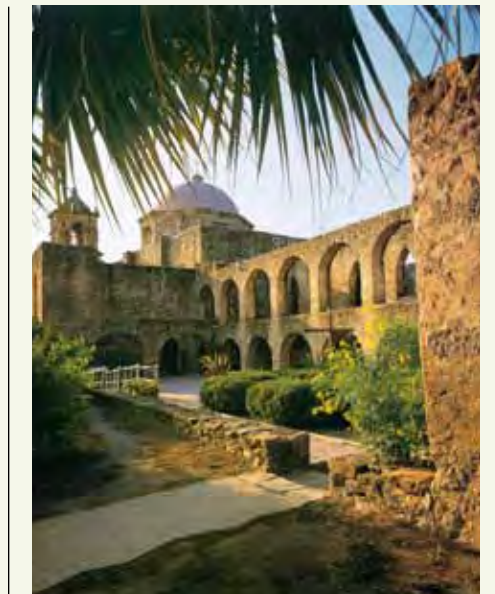


challenge facing many visitors to the San Antonio River Walk is finding time to take in the many activities. The River Walk is lined with a number of fine restaurants, nightclubs, hotels and shops and is also within walking distance of the

Alamo. We encourage you to take some time on the River Walk with us this September!

Register today!

There is still time to register for Envision Conference 2010. Online registration is \$525; on-site registration is \$575. Pre-conference workshops are \$100 each. To register, visit the Envision Conference website at www.envisionconference.org.



Envision 
A multi-disciplinary low vision rehabilitation & research conference **2010**

September 22-25, 2010
Westin Riverwalk Hotel • San Antonio, Texas

ENVISION VISION REHABILITATION BOARD OF DIRECTORS

John Marstall
Margo Watkins
Sheryl Baker
Mary Costello
Richard Keck
Terry Keller
Linda K. Merrill-Parman

CORPORATE OFFICERS

Linda K. Merrill-Parman,
President/CEO
Kent Wilson, Vice President/CFO
Mary E. Shannon, President,
Envision Foundation



Visibility is a quarterly publication of Envision Vision Rehabilitation Center.

610 N. Main, Wichita, KS 67203
(316) 440-1600
www.envisionrehab.com
Servicios bilingües disponibles:
(316) 440-1660

EDITORIAL STAFF

Linda K. Merrill-Parman,
President/CEO
Michael Epp, MS, Director,
Outreach & Continuing Education
Kelsey Rawson,
Communications Associate
Annette Lough,
Development Associate
Kathi A. Buche, Sr. Graphic Designer

GUEST CONTRIBUTORS

Mark S. Borchert, MD
Pamela Garcia-Filion, MPH
Rebecca B. Coakley, MA, CLVT
Richard L. Gaskill, EdD, LCPC, LCP
William L. Park, OD, FAAO

To submit an article or case study to be considered for publication in *Visibility*, please contact Michael Epp, Director of Outreach & Continuing Education, (316) 440-1515 or michael.epp@envisionus.com.

Envision Child Development Center

Envision Child Development Center is currently enrolling for the August 16 opening. Serving visually impaired and typically developing children in an integrated setting, the Envision Child Development Center provides comprehensive early intervention services for children birth through age 5. As a state-of-the-art childcare facility and preschool, the Envision Child Development Center offers a quality education while allowing children to play, make art and music, and enjoy being kids.

Envision Low Vision Grand Rounds Calendar

October 14, 2010 – The Global, Interdisciplinary Team Approach for the Diabetic Patient

January 13, 2011 – Driving and the Low Vision Patient

April 14, 2011 – Vision Rehabilitation for Neurological Vision Loss

July 14, 2011 – Early Intervention and Pediatric Vision Rehabilitation

Envision Continuing Education Calendar

September 22-25, 2010 – Envision Conference, San Antonio, TX.
Multiple CE Accreditations

October 21-22, 2010 – KAER Conference, Wichita, KS. ACVREP CE

November 6, 2010 – Evaluating and Establishing PRL for Low Vision Rehabilitation. Wichita, KS. AOTA, KOTA, ACVREP CE

February 19, 2011 – The Role of Occupational Therapy: Diabetes Management and Low Vision Rehabilitation. Wichita, KS. AOTA CE

Contact Michael Epp, michael.epp@envisionus.com, for more information.

About Envision Vision Rehabilitation

The Envision Vision Rehabilitation Center provides comprehensive, multi-disciplinary low vision rehabilitation and services for people with vision loss. The center's goal is to help patients maximize their independence and realize their best functional vision. The center achieves this by offering a comprehensive low vision rehabilitation program unique to the needs of each patient. Envision provides low vision rehabilitation services regardless of ability to pay. Call to find out about the availability of financial assistance.

REQUEST COPIES OF VISIBILITY

If you would like to share *Visibility* with a colleague, please request a copy from Michael Epp, Director of Outreach & Continuing Education at michael.epp@envisionus.com or call (316) 440-1515. *Visibility* is also available online at www.envisionus.com/Visibility.

The viewpoints expressed by the guest authors of *Visibility* do not necessarily reflect the viewpoints of Envision or its staff.

