Volume 3 Issue 1

NEUROLOGICAL VISUAL IMPAIRMENT DIVISION NEWSLETTER

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WELCOME! Division Updates

Dear Members of the Neurological Visual Impairment Division,

It is always my pleasure to welcome you to our bi-annual newsletter. This will be my last welcome, as I will transition to past chair at the International AER meeting this July in St. Louis. Mindy Ely will step into the role of Chair and if you know her, you will understand how confident I am in her capacity to serve the division well!

As I look forward to the changes to come, I want to stop and thank the people who have been key to the formation and beginnings of the NVID.

Melody Furze has done an amazing job of creating strong newsletters that share the people and news relevant to NVI. Thank you, Melody, for taking on this task, you have made our newsletter great!

Mindy Ely, who has been a friend and colleague for over twenty years has been key in organization and completing tasks. Thank you for being my biggest “big idea” sharer for many years!

Cindy Faris has proven to be a thoughtful, passionate leader and advocate for the division and the children she serves. Thank you, Cindy, for your wisdom and support!

Mary Morse, an idol of mine throughout my career as I learned of her work and writings. Her common sense and get to the point attitude always keep me on my toes! Thank you, Mary for your wisdom and friendship!

Amanda Lueck continues to fill us with passion for those learning about and living with Cerebral Visual Impairments. Thank you, Amanda for your willingness to serve.

In the next month, we will be putting out a call to our members for nominations to serve as president-elect or Secretary. I ask you to consider this call and join us as we continue to grow into a great division!

Thank you all for making this division possible!

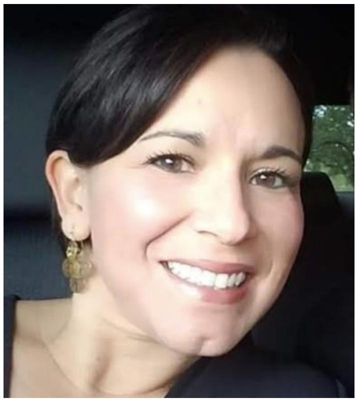
Susan Sullivan

Letter from the Editor

Hi everyone! I'm proud to be putting together another edition of our NVID newsletter. We continue to participate in numerous workgroups and projects all around the country to figure out how best to meet the needs of our population. I am happy to include a reflection on some real-world lessons and ECC skills from Tanner Gers, the Business Development and Sales Lead at the American Federation of the Blind (AFB). And we have a doctor and practitioner perspective on a common CVI tool. As always reach out to me with any ideas for stories or contributions to this newsletter, we'd love to have you! Find me at melodynvid@gmail.com.

TEACHCVI: An Early Interventionist's Perspective

By: Andrea Montano MA, OT/L, DSIII



"TEACHCVI is a partnership that aims to create collaborative tools for teachers and health care professionals. It is meant to build a bridge between teachers/educators and health care professionals so they can work together to benefit the target group: children with Cerebral Visual Impairment (CVI)." (https://www.teachcvi.net/ © 2015 by B&H The National Institute for the Blind, Visually Impaired and Deafblind in Iceland)

Teachers of the visually impaired (TVIs) and other vision specialists in early intervention are tasked with something often unnoticed by others in the field. We are asked to look at a child's puzzling use of vision and then hop in the driver's seat and not only drive but also navigate through uncharted territory. There is simply no map for the conglomeration of circumstances we encounter.

Occasionally it's clear; medical history and brain scans point the way. But usually, we find ourselves sorting through endless possibilities and questions: What is a primary motor impairment? How much is depth perception affecting it? What about sleep patterns and sensory integration? How will this child communicate? Could this be early signs of autism? Is this an actual field cut or is it inattention? How do I explain the difference and why it matters (or whether it should) to a parent?

I have been in the field of early intervention as an OT for 22 years and as a developmental vision specialist with New Mexico School for the Blind and Visually Impaired (NMSBVI) since 2006. The challenge I articulated above is partly what keeps me motivated. I am intrigued by the complex condition called CVI and I'm passionate about understanding each child's unique presentation. My caseload averages about 25 babies and toddlers. Of these, there are usually 6-8 with confirmed CVI diagnoses and 2-4 with suspected CVI. For the latter group, The TEACH CVI Screening Tools have been an invaluable addition to my usual process. They are easy to use and I've found that asking parents the questions yields excellent assessment information.

The following considerations are rarely if ever, part of a typical eye exam: whether the child's use of vision fluctuates; whether the child consistently recognizes common objects, whether the child has difficulty with visual clutter; hesitation while walking; falling or bumping into things; reactions to sounds or commotion in the environment; whether the child stares at lights at the expense of meaningful targets; color preference; ease of reach/grasp. Knowing these things about a child's visual processing is a critical first step when pondering whether he or she might have CVI. The TEACH CVI Screening Tools ask these questions.

After completing the screening with the family, you end up with a score, which is either affirming to your suspicion or it might suggest a wait-and-see approach. Either way, you now have a navigation tool. If it takes you and the family to the eye doctor, it can serve as a bridge to connect the clinical side with the functional side --a bridge on which to meet and stand together and make well-informed decisions. Because it's relatively new to our group at NMSBVI, I've had only a few opportunities to see it through from start (suspecting CVI) to finish (giving it to the doctor, who then confirms a CVI diagnosis). My experiences, however, have all been positive. I highly recommend giving it a try https://www.teachcvi.net/

TEACHCVI: The Pediatric Ophthalmologist Perspective

By: Todd Goldblum, MD

Cerebral Visual Impairment (CVI) is the leading cause of bilateral vision impairment in children. The causes are multifactorial including congenital brain malformations, prematurity, hypoxic-ischemic encephalopathy, trauma, and infections. These children typically have many other medical and developmental issues making assessment of their visual status difficult. CVI is a diagnosis of exclusion, so my job is to be sure there is no ocular cause of the child's visual impairment, such as optic nerve hypoplasia or albinism. Very often, parents ask me if their child is blind or what they can see. I must rely both on history as well as the examination; however, I am only with the child for just a few minutes. There is absolutely no way for me to observe all the signs of CVI during this short amount of time, and parents usually do not verbalize all the visual problems a child has. Teach CVI surveys the parents for common signs and symptoms of CVI, helping identify which children may have CVI, and helping me differentiate CVI from other causes of childhood vision loss. This screening tool is a novel and invaluable tool for evaluating childhood vision loss. We look forward to incorporating this wonderful screening tool into our practice. *Todd Goldblum, MD practices pediatric ophthalmology in Albuquerque, New Mexico*

Adult Perspective: Entrepreneurship: A Personal Reflection

By: Tanner Gers

Entrepreneurship runs through my blood. My dad, and his dad, and my grandfather’s dad are and were entrepreneurs. It came naturally to me.

Identify a problem, communicate or offer a solution, and then execute. It was simple. Until I became severely disabled. I never realized how much the skills I developed during my entrepreneurial childhood would help me after my auto accident, waking up in the hospital totally blind.

Nor would I ever imagine in my wildest dreams that being blind, with zero light perception, would significantly change how the world looks at me.

Because Me? Tanner? I’m just Tanner.

But to other people, I’m different. I’m not just Tanner any more…

I’m a blind guy. I’m disabled. I’m handicapped. And I’m commonly viewed and treated as I’m less than. That’s why I love entrepreneurship. The market doesn’t care that I’m blind. The market only cares about one thing and that’s “What can you do for me?” What can you do better, cheaper, faster, with higher quality, and make the whole process easier? And, until you prove otherwise… The market will treat you like you’re “less than”.

This is exactly why every child with a disability should be developing their entrepreneurial muscles! Such as;

- Starting a lemonade stand
- Washing cars
- Cleaning houses
- Mowing lawns
- Dog walking and sitting
- Lawn/plant watering
- Raking and bagging leaves

- Pulling weeds
- Shoveling snow
- Selling playing cards
- Baby sitting

DEVELOPING A CHILD'S ENTREPRENEURIAL MUSCLES IS CRITICALLY IMPORTANT…

Because entrepreneurship is hard! And so is life. The first time a child knocks on someone's door to sell cleaning, mowing, or car wash service. The first time they try to sell a playing card, candy, or cup of lemonade… they'll probably hear "No." And then they'll hear it again. And again. And again. They may get lucky on the first, or the second, or the third door, but chances are they won't. Chances are they are not natural sales people. Chances are they don't know how to provide more value… And the chances are they don't know how to ask… But, eventually, if they keep at it, practice their pitch, and never give up…They'll get a sale and that first sale, that's something special. It just might get them thinking…How many can I sell? Who else can I sell this to? How fast can I sell this?

DEVELOPING A CHILD'S ENTREPRENEURIAL MUSCLES DEVELOPS SO MANY LIFE-LONG SKILLS…

- Creative and critical thinking skills
- Planning, budgeting, and executing
- Charisma and communication skills
- Understanding/appreciating the value of a dollar
- Sales skills

WHEN YOU THINK OF SOMEONE WITH THESE SKILLS, WHAT KIND OF PERSON DO YOU THINK OF?

Someone who is blind?

Someone with a disability?

Or someone very successful?

BLINDNESS FACT…

To achieve the same level of success as someone without blindness, you will have to work harder than that person, much harder…But the struggles, resistance, the difficulties can all be overcome. They are overcome more easily, quickly, and expeditiously by individuals who have developed their entrepreneurial muscles.

YOU MIGHT BE SOMEONE WHO BELIEVES THAT THINGS ARE MEANT TO BE…

Things happen for a reason…Including my accident… Including my blindness, and I'd agree with you. Things do happen for a reason. If I didn't develop entrepreneurial muscles as a child, I wouldn't have been able to achieve the success I have as a blind adult. School is school. And life is life. Entrepreneurship helped me succeed in both. Make something happen for a reason.

Help develop your students’ entrepreneurial muscles today and they will achieve more success as an adult.

Tanner Gers is the Business Development and Sales Lead at AFB. He lost his vision and suffered a Traumatic Brain Injury in 2004. Learn more about him at https://tannergers.com/about/

Professional in the field: Terese Pawletko, Ph.d.

Q&A Assessment for Students with CVI

By: Melody Furze

Terese Pawletko is our featured professional in this newsletter. She has spent her career specializing in the assessment of children and adolescents with visual impairments, autism, learning disabilities and other developmental issues. Terese lives in Maine where she’s a certified school psychologist and a licensed psychologist (she’s also certified in other states). Pawletko began her career as a teacher of students with visual impairments. Pawletko has presented extensively on visual impairment and developed programs for children with visual impairment and autism. Pawletko has worked in various states in the eastern region of the US and her services have been sought by professionals as far away as Alaska. She has assessed and consulted abroad as well. She also conducts trainings and workshops virtually and in-person for organizations across the US. For this interview I wanted to have a conversation about Pawletko’s experience with evaluations children and her experiences working with and assessing children with CVI. You can find more information on her new website www.teresepawletko.com.

Q: *As someone who has worked extensively assessing children with visual impairment and autism spectrum disorders (ASDs), how do you tease out ASDs, versus other disabilities especially Cortical/Cerebral Visual Impairment/CVI*?

A: Very carefully - research has shown that children with ASD can also have visual processing and visual impairments (e.g., strabismus, prosopagnosia). I do thorough interviews, observations, and record reviews and then assessment and consider the features associated with CVI. It can be complicated. Dr Dutton, for example, would prefer us to leave them all as “neurodevelopmental disorders” and develop individual profiles on the children. I contributed a chapter to the “Vision and the Brain " book and in it we told the story of a young man whose team was convinced he had an ASD. But, he didn’t! They showed me video clips. He exhibited repetitive behaviors - pressing yellow and red buttons. He perseverated on toys with letters and numbers. He couldn’t recognize his therapists unless he heard them speak and the school nurse figured out that he couldn’t see her unless she moved. He had a diagnosis of periventricular leukomalacia (PVL).

When I went to his home to test, his mother shared that he was repeatedly sifting sand onto the tires of their car. His mom introduced me and he went to play his piano and came back and asked if I would look at his keyboard. So he’s demonstrating all of these things - sharing joint attention, referring to me by name, playing. He kept repeating things about bubbles, dinosaurs and the number 26. It was clear to me that he was communicating something with this language. The next day his teacher confirmed that the date that day was the 26th and they had played with bubbles and dinosaurs. He was trying to communicate his school experience. He did not have ASD.

How do you conduct assessment for these populations?

As an evaluator you’re choreographing the way you do the evaluations. I evaluated a little girl who had CVI (dorsal stream dysfunction) and executive functioning challenges (impulsivity) so she had trouble effectively scanning an array and shifting between a stimulus card and four choices. The task is to match pictures (a hand, foot, and nose, for example to a sock or a glove - which goes with which) If I just gave her the card with a picture and asked her to pick a particular one, she couldn’t do it. She couldn’t shift attention. I covered the page with the four choices with black construction paper and gave her the stimulus card and told her “just looking” allowing her several minutes to look at it. I took the card away and slowly revealed the choices, sliding the black construction paper from left to right. I repeated the “reveal” again. I then held the stimulus card beside each of the choices as I slid the construction paper revealing the choices one at a time asking her to tell me when she saw the match.   With these adaptations, she was able to do it, but, if I had just put the stimulus down her response would have been impulsive. I would’ve been testing CVI and executive function not whether she had the concept. You have to control for CVI. There were a number of CVI issues with the materials and her ability to regulate, mobilize, and direct visual attention, attend to the visual clutter, and shift her attention.

As the assessor, it's really up to me to choreograph what's going on. I need to get their visual attention and provide sensitive presentation of material to get the best shot at seeing what kids are processing and seeing and understanding.

I see it as my responsibility to get the most accurate information. No kid is untestable -it is up to us to set up the assessment situation to match abilities and function to task demands - I am "testing limits" vs. obtaining scores in a number of situations and while scores are important and often needed by schools, I am interested in maximum or optimal function.

Have you evaluated children with ASDs, who were discovered to actually have CVI?

I did evaluate a child with an Asperger's diagnosis. I didn't do the initial evaluation, but was consulting with the team and asked to do his triennial. He had not been using many of the visual and organizational supports we had developed for him and was also showing considerable anxiety. I interviewed his mom as part of the evaluation and she said, "I have a question - he was asking if I had seen his iPad - it was sitting right in front of him on the kitchen table among other things." They were in a theatre a few weeks before and he told her he couldn't see the faces of people on the balcony. He had difficulty with writing, motor planning (including shaving his face while looking in a mirror) and couldn't deal with visual clutter (so not using the visual supports made sense), and he also had amblyopia. He was born only slightly premature. He had never been identified as a child with a visual impairment and yet appeared to have dorsal stream dysfunction. We shifted to tangible (e.g., shaving by touch, not looking in the mirror) and verbal (e.g., speech to text) systems for "writing" among other things.

What are the challenges you've experienced with collaborators in special education?

With the first child I mentioned, his TVIs didn't believe he had CVI. They said it had resolved. They didn't understand how to use the assessment tool. It was challenging. The PT and OT were great and they're the ones who detected that something was going on with the boy's visual system.

I've been fortunate to work with some amazing colleagues and families. I want to share this podcast Stronger Everyday - about being a parent to a child with a disability. His daughter has CVI and autism and he does an amazing job of telling their story as a family and a child with a disability. http://www.portlandrootsmedia.com/stronger-every-day-blog-1

What other diagnoses have you seen in children with visual impairment?

There are a range of kids with spectrum disorders and visual impairment. Norrie's disease - has some genetic link. I've also seen children with Peter's Anomaly, Albinism, Anophthalmia and Leber's Congenital Amaurosis. There are a number of others as well.

How do you tease out what's absence of vision and what is not in regard to ASDs?

Children with visual impairments are often slightly delayed in social interactions but are still able to relate to adults and peers, engage in social games, etc. There may be periods of echolalia (true for typically developing) but non-prolonged periods. We have to look at the quality and nature of play - is it rigid, perseverative or does it vary? Is there a driven quality to it? The ASD cluster includes a cluster: social relatedness, understanding and use of language, communication issues, repetitive behavior, sensory sensitivities and communication. The waters can get muddy as there are no specific instruments developed for diagnosing ASD in children with visual impairments…

Can you expand on the "sensory sensitivities?"

Sensory sensitivities include textures (including clothing, foods), olfactory (smells), auditory sensitivity, proprioceptive (body in space, degree of pressure) and visual. The child may be over-responsive or under-responsive to these.

What is your advice for those children who will need to use braille, but have tactile sensory sensitivity?

These are really not based on research, but just ideas. You need to "ready their hands to receive information" - working down to the fingertips, do arm massage down to fingertips, to get their arm and hand ready for touch and sensory input. Have them use their hands in a variety of ways, varying the input. Can they grip a milk carton? Can they poke? Can they pour? Can they sift? Tactile skills are really refined in a variety of ways with a variety of materials.

Great recommendations, thank you, any last words?

I say always listen with a third ear and look with a third eye. Suspend your assumptions about a child's capabilities immediately. I want to be clear that I'm not all about finding autism in students with visual impairment. My goal is to find strategies that work for children so they can be successful and their teams can work with them in the most effective way possible.

Learn more about Terese's work at https://www.teresepawletko.com/

RESEARCH ROUNDUP

ANCHOR CENTER AND ROCKY MOUNTAIN CHILDREN'S HOSPITAL – DENVER

Update on the NAVEG (Neonatal Assessment Visual European Grid) Project

By: Cathy Smyth Ph.D

Update of the NAVEG project: January 2020

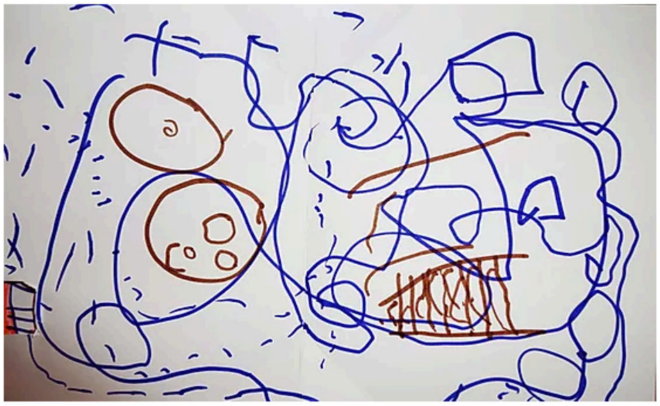
Anchor Center for Blind Children, a non-profit organization that supports families with young children with visual impairment from birth to six, and a Neonatal Intensive Care Unit (NICU) at Rocky Mountain Children's Hospital have been in collaboration with families to identify visual function concerns of pre-term infants and follow through with ophthalmological services to families and early intervention. The NAVEG project continues to move forward collecting data on the visual developmental abilities of premature newborns from 35-40 weeks. Dr. Robert King and Cathy Smyth, Ph.D. presented to an enthusiastic audience of NICU and EI providers at the Zero to Three conference this past October. This January, Perkins is sponsoring a live webinar on the NAVEG Project. The staff is working on early intervention strategies and assessments we can use to support families of young children identified with CVI in our program. We hope to begin an intervention-based research project over the next two years, starting with parent and child interaction assessments as a quality indicator in our infant, toddler, and home visit programs.

As the Director of Research at Anchor Center for Blind Children, Cathy Smyth will oversee the NAVEG study implementation as infants move from the hospital to home environment. Data collected during this study will determine program strategies and evaluate best practices with families. Anyone wishing to know more about this research should contact Cathy Smyth at 303-377-9732 x120.

PRODUCT CORNER: TEACHCVI

www.teachcvi.net

***authors note –** *The product corner is to introduce our audience to potential tools. We are not aware that this product (in the internet form) has been validated. We're sharing tools so that you are aware of and can evaluate resources on your own.*



"My home: stairs, people and windows."
By S.H. a five year old girl with CVI.

(child's picture of face and scribbles and circles from TEACHCVI homepage with quote from the illustrator "My home: stairs, people and windows." By SH, a 5-year old girl with CVI)

We featured TEACHCVI earlier in this issue, so it seemed fitting to also give it some space in our Product Corner. This is a great resource that aims to provide tools for both healthcare professionals and educators to screen for CVI. Their site includes assessment tools, guidelines, team resources, teaching materials, presentations and workshops.