I can do hard things
Rachel Bennett

Thank you, Amy, for those kind words and a warm welcome. It is such a joy to be here. I’m so honored with this opportunity. I want to recognize all the other CVI parents out there who have been leading the way and sharing their stories. Your stories and your work have helped me get to this moment right here. I’m forever grateful.

I remember one morning when Henry was two months old. It was 7 am and I was pushing him in the stroller around the block. He had slept only 2 hours the night before and I was a wreck. I must have looked as bad as I felt because a woman I had never met came up to me. She looked me straight in the eye to make sure she had my attention and said, “It gets better. It gets better.” To her, she was imparting wisdom and compassion to the exhausted mother of a neurotypical child at the difficult but all-to-ordinary beginning of the journey of life. She could have no idea of the extra challenges and emotional upheaval my family and I would face over the years to come. And yet, I have held onto that chance encounter every day since.

I’m here looking at you. Whoever needs to hear this. Wherever you are on this journey. It gets better. And even if it gets worse first. Even if you find yourself navigating the darkest moments of your life. There is hope. It can get better. Have faith that it WILL get better.

Today I want to share my journey with you as a parent of a child with CVI and peek into the collective journey of CVI families. But I want to go beyond my child's diagnosis story and my personal lessons learned. I want to talk about the journey of personal growth that we are all forced to travel while raising a child with a disability.

My Henry. My first child. My beautiful little boy, who somehow makes everyone fall in love with him as he peppers them with non sequitur questions about their home appliances, where their car is parked, and what color their pants are. He is figuring out how to exist in a world not designed for him. Henry is 8 years old and he has CVI and ocular impairments: nystagmus, optic nerve atrophy, exotropia, myopia, as well as delays and complexities in speech, motor skills, and processing. It has been a wild ride, to say the least, parenting this complicated human being.

Before diving deep into the emotional challenges of being a CVI parent, let me share with you a little bit about CVI. It is a brain-based visual impairment, in which interruption or damage to the visual system in the brain results in difficulties with visual attention and visual recognition.

As with many children who have CVI, Henry’s visual system is less efficient and doesn’t have that instantaneous capture of information that those with an efficient, fully intact visual system have. He has to work harder, so much harder when attempting visual tasks. And most materials and activities have to be adapted for Henry to have access.
Kids with CVI have unique visual behaviors, which include relative strengths such as attention to color, light, and movement to support vision use. But, in addition to visual attention and recognition, they also struggle to recognize faces, interpret facial expressions, integrate multiple sensory inputs, coordinate visual motor skills, perceive fast movement, and access a full visual field. As a result, they miss out on the visual curiosity and incidental learning taken for granted by so many of us. But there is hope, thanks to neuroplasticity, there is some expectation that functional vision may improve with individualized supports and adaptations.

CVI is the leading cause of pediatric visual impairment. But—and there is always a but—the medical and educational systems still have a lot of work to do to catch up and fully meet the needs of individuals with CVI.

As parents of kids with disabilities, we are catapulted into an arena of vulnerability. When I speak about vulnerability, I look to Brené Brown’s research for a definition. She studies courage, vulnerability, shame, and empathy and is the author of five bestselling books. And I love her podcasts. Her work has given me language for my experiences, my feelings, and my emotions. Brown’s work is helping me develop emotional intelligence and awareness, and helping me find wholeness in a life with so much uncertainty.

Brené Brown defines vulnerability as uncertainty, risk, and emotional exposure. Vulnerability is not a weakness. It is the bridge to courage—having the courage to show up, be seen, and love wholeheartedly when we have no control over the outcome. And that is really scary. It takes a lot of work and awareness to be in this space. We have to truly believe that we are worthy, we are enough, and that we can do hard things over and over again.

The arena of vulnerability can feel really lonely. It can just suck. It is a space of tension and paradox. And it is what we bring with us in every interaction with a teacher, doctor, therapist, friend, and family member.

Raising Henry for the past eight years is living with uncertainty. I can’t count how many times I thought to myself: I have no idea what to do. And I’m so afraid for my kid.

I had so much to figure out. In his early years, I was scared every day for his health and well-being. I was exhausted and I couldn’t sleep. I was anxious. I was traumatized.

And so I think about all of us families raising a child with CVI, with a visual impairment, with complex needs. And I think about all that we have had to adjust to, all the different iterations of a new normal. And then to know that we will have to continue to adjust over and over again in the face of uncertainty, pain, and grief.

I remember the moment that I realized I was looking at a future filled with hard things. I was sitting in Children’s National Hospital in DC. Henry was about a year old. He was sedated and in the MRI machine. It was a moment that came after an already tough year.
Henry had been born at term, but he was failing to thrive. He was never able to get out of the zeroth percentile for weight, he didn’t sleep well, he wasn’t meeting any milestones. At five or six months, I noticed his eyes started shaking, which I now understand to be nystagmus. But at the time, I remember thinking, “oh I bet all babies’ eyes shake.” Little did I know that the visual system is pretty much close to set at 6 months. That is what led us to the pediatric ophthalmologist, the neurologist, other specialists, and then to his first MRI scan.

And I was just sitting there while he was in the MRI machine, so overwhelmed that I couldn’t read anything. I couldn’t talk to anyone. I could barely breathe. That was the moment I realized that this wasn’t going to be the last time I would be in a situation like this. I needed to figure out a way to do hard things. I needed to figure how to be a parent in a situation I never expected and did not fully understand.

Just two months later, Henry was in the ICU for over a week for serious complications from a stomach bug. And there was a moment in the emergency room where Henry was fighting to hold on and one of the doctors asked me to sing to him. I couldn’t at first. I could barely hold myself up. Eventually, I made some type of sound. And eventually, the ER team got him stable.

I put the question to the CVI Now parent community: What was the moment you realized that you were going to have to do a lot of hard things raising your child, that this was going to be a tough lifelong journey?

There were three common themes in their responses to this question.

For many, this realization came with an initial diagnosis or even unfolded over a series of multiple diagnoses. For one family, a diagnosis of epilepsy was followed by one for CVI and the need for a wheelchair. For another parent, this moment came with MRI results showing brain damage, followed a month later by a CP diagnosis and then a CVI diagnosis.

One CVI mom said: “It was on that day that I realized my child has a lifelong disability that will forever impact everything she does in her daily life - and it was going to be a constant struggle and fight for her to access the world around her. Until then, I had been prepared to deal with medical scares and motor delays...but the CVI diagnosis changed everything about her access to the world, education, and future employment.”

For another contingent of parents, the realization came with a big event or a series of events. A big seizure at 2 years old, rushing their 3-month-old to the hospital after a major cardiac event, watching their child go through several brain surgeries all before the age of three, or after a traumatic brain injury before the age of 6 months.

And yet for another group, the realization came during otherwise mundane moments. One family’s outing to a busy restaurant sent their one-year-old with CVI into a sensory meltdown, complete with screaming and hyperventilating, leaving the parents exhausted and heartbroken at the understanding that their lives as parents would not, and could not, be normal.
These moments are part of the permanent layer of grief underlying everything else we are working through with our kids.

Grief is the broad experience of loss. It is an integral part of the human experience: so common as to be universal, and yet so profound and traumatic. This past year, during this pandemic, we have all experienced collective grief. The loss of so many important parts of our everyday lives. The loss of gathering with friends and family, the loss of in-person school (oh my gosh this one hit me so hard), the loss of important events. For the most unfortunate, the loss of our health or even the loss of loved ones who have succumbed to illness.

So when I talk about the grief that comes with being a parent of a child with CVI and other needs, I’m talking about loss. For me, it was the loss of the popular narrative of motherhood. The loss of predictable expectations, predictable milestones, and predictable aspirations for my child. And the loss of a life for Henry without the extra challenges presented by disability. Life will be harder for Henry. Unfairly, he will have to negotiate a world not designed for his needs and gifts. Unfairly, he lives in a society that is not accessible.

One CVI mom’s insight deeply resonates with me: “Grief will often hit me at seemingly random times... recently my son was stammering and searching for a word, and I just was overcome with sadness. His little brain is so full of brilliance, and yet there are times when he just can’t get the right words out. It’s the little moments that get me.”

Kira speaks for so many of us. It’s the little moments compounded with the big moments that we are carrying all the time.

At 2 ½, Henry was finally in a better place. He was out of the zeroth percentile. My husband and I were slowly climbing out of survival mode. We had identified a bunch of Henry’s food allergies and were putting some weight on him thanks, in particular, to sweet potatoes and bananas. He had started Early Intervention with OT, PT and Speech, followed soon after by vision services for his ocular issues. We were still negotiating a gauntlet of specialists. We still had never even heard the phrase CVI, which would later come to define our lives. But we were learning to live the new normal.

There was still so much that didn’t make sense. We puzzled over Henry’s visual behaviors. Why didn’t he look at me? Why didn’t he recognize me when I walked in the room? Why wasn’t he interested in toys, books, and videos? Why did he freak out in new and busy environments? Why did he trip and fall so much? We had so many questions and very few answers.

Henry’s vision was a mystery—at least that is what every doctor told me. We saw a pediatric ophthalmologist, neurologist, and neuro-ophthalmologist. We even saw a pediatric genetic ophthalmologist at the National Eye Institute at NIH annually for three consecutive years. Not one of them so much as mentioned CVI as a possibility. So of course, I took the wait-and-see approach. If these doctors and teachers weren’t sure, then Henry’s vision must be a true
mystery. His pediatric ophthalmologist kept telling me that his vision was fine and that Henry had attention and behavioral issues that needed to be addressed. They kept focusing on his inattentiveness and impulsivity.

To this day, I wrestle with guilt over actions not taken. I wish I had pushed against the “experts.” I wish I had dug deeper. I wish I had trusted my gut a little more.

We eventually got Henry’s entire exome tested to help us figure out a cause, a syndrome, something. Something to help me know that this wasn’t all my fault. That I didn’t do something wrong during Henry’s pregnancy. Something to make all this uncertainty feel a little less chaotic.

Genetic testing identified a variant in the ASTN-1 gene, which is responsible for sending neurons to their final position in the brain during fetal development. It had never been studied in humans but seemed to be the missing puzzle piece. This one little random mutation had altered the life of our son and our entire family. But for the magnitude of that revelation, it offered us no path forward. We were left with even more questions.

I remember feeling really lonely and angry throughout Henry’s early years. Why was this happening to my child? Why was this happening to me? I couldn’t take Henry to the playground without being overwhelmed with sadness. Other kids were walking, running, talking, climbing, and playing with each other. Other parents were able to hang back talking to one another. But I had to be by Henry’s side every moment—to help him walk, climb and swing. I watched in constant fear that he might fall or trip. The stress tightened every muscle in my body. And I would come home and let the grief wash over me. All just from going to the playground.

Despite the experts with long titles telling us otherwise, it was Henry’s first Preschool classroom teacher that set us on the path to a CVI diagnosis. She kept asking me about his vision. Each time, I repeated what the experts had told us: that he had attention and behavioral issues. I cannot emphasize how grateful I am that she did not back down.

Shortly after that, we visited a vision pre-K class and saw it immediately. These were Henry’s people! We watched as they felt around for their food during snack time, just like Henry. Their hands glided along the wall as they walked through the hallway, just like Henry. They played with toys in a multisensory way—shaking, touching, banging on the ground, putting them close up to their face—just like Henry. Here was another moment of realization, that my son was truly visually impaired. That moment taught us more about our son than all the preceding years of work with specialists.

Prior to Henry’s IEP meeting—he was five years old at this point—we had still never heard of CVI. In that meeting, the vision specialist said to us, “You know, Henry has characteristic behaviors of CVI.” I sat there, mouth open, frozen with confusion, and asked, “What is CVI?”

We had spent years working with teachers of the visually impaired, ophthalmologists, neurologists… pediatric neuro-ophthalmologists. Not a single one of them had so much as
uttered the phrase “CVI”. A small sliver of my grief transformed into anger and resentment. And in turn, some of that transformed into hope. There was finally a path forward.

My journey toward understanding started with the foundational books on CVI: one by Dr. Dutton and Dr. Lueck and one by Dr. Roman-Lantzky. I remember underlining nearly every word in these books because they so aptly described Henry. This came with the revelation that no one was going to understand my son for me. I had to be the one to fight for Henry’s access. CVI parents talk about this all the time. This is a really hard thing we have to do… to be the one who has to cut the path forward for our kids.

One CVI parent said it so well: “The constant research, advocacy, and weight of having to be the expert that educates the “experts” in daily life. It's overwhelming. I wish it could be as simple as ‘oh your child has CVI, so here are some resources, tips, and local support groups. Here is what we are doing in our community and schools for kids like yours.’ The lack of local knowledge and support is depressing. Because I feel like I can never turn my back for one second - and worry that if I can't get my child the right supports, she won't have access to reach her fullest educational potential. It's an overwhelming sense of responsibility and guilt because I'm just one person.”

This resonates with me so deeply. For the past several years it’s been a whirlwind trying to learn as much as I can about CVI while processing the range of emotions that come with this diagnosis. I became an avid student of CVI. I researched, read, attended trainings, and took online courses to learn as much as possible about the visual system, the brain, assessments, adaptations, and educational approaches. Matt Tietjen’s course on his What's the Complexity Framework, in particular, was a pivotal point in my learning. I have become a neuroscience nerd. These days, I read research articles and books about the brain on a near-daily basis.

Early in my learning journey, a CVI mom told me about a teleconference call for CVI parents hosted by the New York Lighthouse Guild. This was an emotional and informational lifeline for me in the early days. Connecting with CVI parents has been one of my greatest joys. This community gave us the space to revel in our shared experiences, ask questions, share resources and strategies, and get fired up.

The brilliant and fierce community of CVI parents gets me through the emotional exhaustion and unsure moments. To know that I have a whole army of CVI families with me when I’m facing an IEP meeting or dealing with yet another one of Henry’s meltdowns. To know I am not alone... is just everything. It makes me feel less broken. It helps show me that I can do hard things.

When Henry was 5 ½, I connected with the Maryland Deafblind project, Connections Beyond Sight and Sound, to see about getting a CVI assessment. We then found an ophthalmologist who knew about CVI and officially diagnosed Henry with CVI.

I knew his vision was not typical, but I didn’t know how significantly visually impaired my child was until after FIVE years of being his mom. This guilt over opportunities missed will always be
with me. What if I figured out Henry’s CVI on my own? What if I could have somehow filled in all
the holes left by our grueling schedule of medical and therapeutic appointments? There are still
days when I feel like I haven’t forgiven myself.

And this is a story all-to-common. Some families don’t learn about their child’s CVI until when
their child is a teenager or older. Until their child is 15, 19, 26, or 34. This is infuriating. And even
when parents get a CVI diagnosis for their child early, some are told there is nothing they can do
about it, which is simply untrue.

Children with CVI are underdiagnosed and often misdiagnosed. What if we never learned of
Henry’s CVI? He would most likely be diagnosed with ADHD and a mood disorder. He had a lot
of really difficult behaviors… but I realize now that his outbursts are him communicating his
need for access or his visual fatigue.

At every level, the system failed Henry and robbed him of years of appropriate interventions and
opportunities to improve his use of vision. We know the critical role that vision plays in all areas
of development: gross motor, fine motor, communication, learning, behavior, and social skills.
And again, I wonder what would be different now if we knew?

A few months after Henry’s CVI diagnosis, we went back to the National Eye Institute at NIH for
his fourth visit. Armed with fresh insight into Henry’s condition, we both wore our Start Seeing
CVI shirts created by an incredible CVI mom and advocate. This time Henry’s doctors heard all
about CVI. This was my first time really speaking up big for Henry and it was really scary. But I
knew that I had to talk about CVI. We left the appointment with the lead doctor looking up CVI
on his research database! I then contacted the head of low vision at NEI about ways that CVI
can become a research priority. And just last year the CVI community responded in a big way to
NEI’s Request for Information about their future strategic plan. As a result, CVI was the single
most mentioned issue. And now CVI is part of NEI’s strategic plan and families can learn about
CVI on their website.

Speaking up matters. CVI parents are on the frontlines of changing the world for kids with CVI.
This is a constant and difficult role. Especially when your kid is the first kid with CVI that a
doctor, teacher, or therapist has worked with. But every time we talk about CVI, we are building
awareness.

The year leading up to Kindergarten, Henry had a responsive and open-minded TVI. She was
the vision Pre-K teacher. She was a new TVI, fresh out of graduate school, and loved learning
about CVI. She really joined me in this arena of vulnerability. She asked a lot of questions and
she took a lot of data on Henry during learning tasks.

Beyond learning how to parent a child with special needs, I also had to learn how to advocate
for his education. As I learned more about the critical need for O&M services for children with
CVI, I challenged the O&M assessment that said he didn’t need services based on the
observation that he could walk in the empty school hallway and get around his familiar classroom just fine.

Our kids with CVI have incredible compensatory skills. But clearly, the O&M evaluator didn't understand the profound challenge kids with CVI have when navigating an unfamiliar place or a busy, crowded, and noisy environment. We are learning more and more about what might happen to vision in the presence of clutter, multiple sensory inputs, or with visual fatigue. Individuals with CVI have shared that the visual field is reduced and constricted, vision becomes blurry, and familiar items are only recognizable by touch.

Over the last couple years, we have learned so much about the particulars of Henry's vision. Beyond his challenges with visual clutter and fatigue, he also has difficulty with finding and reversing a route; difficulty with processing fast motion such as a car driving down the street, a swing on a playground, or kids running around him; and a lower visual field loss. He requires an adult with him at all times to help navigate environments.

In this IEP meeting, some of Henry's educators and administrators challenged my assertion that he needed O&M services. They were not really buying it. It is so hard to speak clearly and articulately when the issue is so personal and important. I already wear my heart on my sleeve. And now I'm talking about my kid. But eventually, we broke through. He got a new assessment from an O&M who understood CVI, which in turn led to services. Again, I am so proud that I spoke up in a big way. Henry took to his white cane almost immediately and it is a tool he uses every day for safe navigation and access.

One of Henry's classmates in his pre-K vision class was totally blind and I learned that his family lived close to us. We all met up together at a local playground. I watched as the mom stayed close by her son's side and how she freaked out every instance her son approached a high drop-off or other potentially dangerous obstacles. We were both running around following our boys, barely able to complete a sentence or hold a full conversation. It was the first time the playground didn't feel so sad to me. To be able to spend time with a mom like me, a mom who has to go through this world raising a kid who is visually impaired, made me feel more whole and less alone. I was quickly learning that community, in particular relationships with parents and others who get it, is what will fill me up so I can sustain myself on this long journey. So I can believe that I can do hard things.

As parents, we live with CVI 24/7. Henry exists in a world not designed for him. His frustration, anxiety and behavior show his need for access every day. Children learn a tremendous amount through incidental learning, which happens through interactions and observations with the world around them. Henry misses so much of this. Incidental learning teaches foundational concepts that are the building blocks for future learning and independence. But with Henry, we have to teach him everything directly: How to use utensils, how to navigate a new environment, how to draw and write, how to recognize something unfamiliar, how to wave goodbye, how to get dressed, how to use the toilet, how to pucker his lips for a kiss, and on and on.
I asked the CVI Now parent community another question: Right now, what is the hardest thing about being a CVI parent?

Overwhelmingly, parents echoed my personal feelings that the hardest thing is the relentlessness of parenting a kid with a disability. There is the constant need to advocate, learn, be the expert, and teach others about CVI due to the lack of understanding and awareness of CVI. To guide and support the very system that is supposed to be guiding and supporting us.

One parent noted: “I feel like I am the only one that can help my kid navigate and interpret her world in an understandable way because I’m the one who has figured out CVI and did all the learning.”

Throughout this prolonged period of intense personal pressure to take care of our children and carve out a future that has no place reserved for them, parents feel unsupported by their educational systems.

Another parent captured this sentiment: “The lack of support and direction are very difficult for me. I often feel like I am the most knowledgeable regarding CVI when meeting with professionals, so I am frequently frustrated. I am constantly searching for information on how to help my son. I worry that if I were not so involved, he would not make progress.”

The grim irony is that the IEP process itself, intended to ensure adequate care and education for our children, often creates another layer of trauma for parents of children with special needs. Special needs are, in fact, human needs.

The constant advocacy with school teams in order for their child to have access to an appropriate and meaningful education is a ubiquitous experience among CVI families.

- One parent noted: “I feel ashamed that I don’t have all the fight in me that my child needs.” This one hit me deep. The spiral into guilt and shame is real. The fight is so hard. And it does not have to be this way.
- Another CVI parent stated, “Plain and simple. Access to any kind of appropriate help in our state.”

Beyond the burden of intense care and relentless advocacy, CVI parents face the uncertainty of our childrens’ future. Parents have shared with me so many concerns and worries about the pitfalls, setbacks, and hurdles that await their children. They ruminate on keeping their child safe and helping them to navigate the world as they grow up.

- One parent said: “The lack of support and understanding of CVI out in the world makes planning transition as my son approaches adulthood an overwhelming prospect. Once again I am realizing it is on me to forge ahead, cut new paths and create opportunities for him.”

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A parent summed it up: “concerns with safety, the frustration with not knowing what he sees, how best to help him, the gap widening between him and his peers and how this affects him socially and academically, the future, and on and on. There’s so much! It becomes exhausting to think about it all!!"

It’s not okay that it’s this hard. We need to do better. We need system-wide change.

Henry’s Kindergarten year was really hard for us. It was a big transition. Henry’s teacher was kind, smart, organized, and open to learning about CVI, but Henry needed a whole-team approach. Looking back, it wasn’t an appropriate placement for him.

That year, Henry had a lot of meltdowns and outward behaviors and, as a result, our family experienced a lot of stress. I would have to pick him up early from field trips or from school. He was kicking, screaming, climbing on tables, hitting, and crumpling up worksheets. Worksheets! For a pre-literate child with CVI?! Heck yes, he was crumpling them up. I wanted to crumple them up on his behalf. Clearly, Henry didn’t have access. His visual fatigue was overwhelming.

Henry’s team used general CVI accommodations: the black trifold, color, but, in retrospect, there never was an instructional approach rooted in assessment and data. There was no Learning Media Assessment to assess appropriate learning materials nor a comprehensive vision assessment. I even went so far as to provide a CVI assessment from Dr. Roman herself, but even this was never fully owned by Henry’s team. It made me feel like they didn’t believe in his ability to become a reader, writer, and problem solver.

Every child with CVI, every child with a visual impairment, is ready to start their path to literacy, and this path will look different for each, but our kids are ready.

That year, Henry’s IEP meetings took everything out of me. I had so much I wanted to say and problem solve with the team. But it took all of my strength just to maintain my composure, just to not break down and cry until after the meeting. Afterward, I remember hiding under a blanket to watch an hour of stupid TV, just to recover a bit.

As a former special educator myself, I sympathize with his team. I know how daunting it is to have to learn so much about complex students… on top of an already overwhelming job. But this, not knowing how to help a student, is never a reason to put up a defensive wall between you and the parent. We’re just trying to share what we know, our expertise about our child is a valuable part of their IEP program.

Educators and school staff, join us in this arena of vulnerability. Help us learn and problem solve. Help us develop an accessible school day for our kids.

This was the year where I was overextending myself by trying to do it all: adapt all of Henry’s materials, take online courses, be his OT, PT, speech therapist, get outside evaluations, and
constantly teach his team about CVI. I was in a spiral of fatigue, stress, fear, and guilt. It was affecting my relationship with my husband and my relationship with Henry.

I was looking at Henry’s future in this huge school district that really had no appropriate placement for him and no creative learning solutions. I was looking ahead to what this would do to my mental health and my family. I also knew that I needed more help and I needed to learn how to ask for help.

Our lives changed for the better 2 years ago when we decided to move to the Boston area. We had long floated the idea: I grew up in Boston and still had my family and friends here. But it takes a lot to uproot your entire life. To change jobs, sell a house, leave friends, walk away from a familiar school system. But sometimes you have to hit rock bottom before you can rise up. Our tough year ultimately inspired us to do the hard thing and take radical action.

So far, our gamble has paid off. Henry’s pediatric ophthalmologist knows CVI well and registered Henry for the Massachusetts Commission for the Blind, designating him as legally blind. This has opened the door to services that he has never had before.

Henry’s new team sees him for his strengths and abilities. They see his CVI. Henry now spends significant time in a general education classroom socializing and learning with his peers and has a great team of educators supporting him and providing individualized services. He benefits from a flexible and creative learning model. This arrangement enables him to benefit both from social time with kids his age and from working in a quiet space with his special educator and TVI.

His TVI is outstanding. For the first time in Henry’s life, she completed a comprehensive assessment. I now have a clear picture of the educational impact of Henry’s complex visual impairments.

This is what the comprehensive vision assessment included: A functional vision assessment for his ocular conditions (nystagmus, ONA, exotropia, myopia). The CVI-specific assessments included Roman’s CVI Range, Dutton’s CVI Inventory, Tietjen’s Complexity Framework. There is the Learning Media Assessment, which also included Tietjen’s 2D image assessment. It was an 18-page report with 6 pages of recommendations.

And for the first time, every team member evaluated Henry as part of the initial IEP process. It was the most comprehensive whole-child assessment experience I’ve ever had for Henry. His IEP was rooted in assessment, baseline data were included in present levels, and goals and objectives were built from this data. His goals and objectives are connected to grade-level standards, even if his individual approach looks different.

Henry’s making real progress. He’s happy. Even when he has tough cycles, and life under COVID has certainly brought a lot of those, his school team remains unphased. They don’t blame Henry. They problem-solve and collaborate.
Thanks to his TVI, Henry is now on a path to literacy. We know how to present print in a manner that is accessible to him, we know which assistive technology that works for him, and we know that he’s a dual media learner, benefiting from the use of tactile and visual elements. His TVI figured out that when he engages in tactile activities before a challenging visual activity, his visual attention and recognition are better. His visual system is more awake.

Henry now sees himself as a reader and a writer. He’s more confident. Just last month, his TVI shared with me that Henry is able to read some of his familiar sight words in normal black and white print on the iPad. He doesn’t need the print and background to be a certain color. The implications of this took a while to set in. I just couldn’t believe it. I said to her: Do you know what this means? Someday really soon he can pick up a book and read the words on the page. I then just lost it and started to ugly cry.

And this all started with a comprehensive assessment. And with a team, who consistently collects data and problem solve.

I asked the CVI Now parent community what gives them hope and what keeps them going. And of course, they showed me there is a lot to be hopeful for.

Hope is found in our kids. In their progress, in meeting those inchstones. Witnessing their happiness and when they learn something new. Our kids are uniquely incredible. They have developed so many compensatory skills to merely exist in this world.

- One parent so wonderfully said: “What gives me hope is my daughter’s determination and her persistence! She never gives up and she doesn't feel sorry for herself....so I take my cues from her: no room for pity parties and stay the course. That's our warrior's motto! At 17, she continues to find ways to adapt and it lights my soul on fire to keep going with her!”

Hope is found in more CVI awareness and commitment to learning about CVI.

- A parent wrote: “When a provider, therapist, educator, or administrator makes a genuine, educated investment in our daughter's success.”
- Another parent said: “There is SO much more visibility around CVI than there was when my son was diagnosed just 2.5 years ago! That gives me hope. I really believe that CVI will, someday, be well understood, and we will not have to fight so hard for our kids to be supported.”

Hope is found in research and innovation.

- One parent said it so well: “Hope comes from knowing that the brain is like the ocean, we have only discovered and understood a small part of it- which means there is still a lot left to explore: in how the brain works, how neuroplasticity works, and how our kids’ vision works.”

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And she continued: “The speed of technology is making the world so much more accessible to our children allowing them to reach their full potential.”

Hope is found in the stories of other CVI families.

A parent wrote: “CVI groups such as CVI Now give me hope. As I read other parents' stories of their child's challenges and successes, it offers connection with others in similar life experiences, empathy, hope, joy and perseverance to lead this charge together to ensure our kids have access, opportunity and resources to meet their full potential.”

I asked what parents do to take care of themselves so they can show up for their child with CVI.

When flight attendants give the in-case-of-emergency speech prior to take-off, they instruct you to always put on your own oxygen mask before attending to your child's mask. My husband and I take this as broad advice for life. So do other CVI parents.

One parent said: “I have to work out for myself, it's always been a part of my life. But the increased incentive is that since my growing son is nonambulatory, it is now for him too.”

Another said: “Taking care of my own medical needs, exercise, sleep, nutrition, meditation, music, reading for pleasure, and nurturing my friendships and relationships. It takes a ton of energy (mental, physical, emotional, social, spiritual) to parent, so I have learned that I need an extra-large "oxygen mask" that I must wear first to be able to care best for my child.”

What is your oxygen mask? What do you do to take care of yourself, really take care of yourself, so you can show up for your child?

For me, one of those actions is leaning into my communities. My community of family and close friends allow me to be vulnerable and ask for help. They allow me to tell my truth and share my needs without guilt or apology.

My community of fellow CVI moms and parents give me the support, love, and space to try to make sense of the messiness of CVI.

My incredible fitness community, a gym of other women waking up and showing up for grueling 5:15 AM workouts, help me develop physical and mental strength. Movement heals. Breathing heals. Sweat heals. But perhaps more importantly, they serve as my daily reminder that I can do hard things.

I strive daily to accept life on its own terms and cultivate gratitude.

I strive to love wholeheartedly and accept Henry for all that he is. I try to give him full multisensory experiences, to be vulnerable in the world, to try new things, even if we are only at a new place for 5 minutes. The brain is ever-changing in response to interactions, experiences,
and the demands of the environment. I want him to live fully so he can continue to make progress.

I am now thankful for the healing process from grief because it’s teaching me so much (in addition to my therapist). It’s easy to lose faith (whatever this word means to you) with all the barriers and all the uncertainty. But it’s an act of courage to have faith even when we don’t know the outcome and when we can’t control the chaos. I have faith in myself. I have faith in Henry. I know he will do great things.

Right now, we are in a big moment for the CVI community. We’re on a precipice of change. There is more awareness of CVI in the medical and educational communities. Even though that change has yet to manifest for many CVI families across the country. We are seeing more CVI research. And the collective voice of CVI families continues to grow.

Perkins continues to step up for CVI in a big way and big things will keep coming.

Every child with CVI has the right to an early diagnosis, effective vision services, and access to appropriate educational programs. Every child with CVI has the right to access opportunities, again and again, that will empower them to reach their full potential. We must support individuals with CVI both holistically and as unique individuals, and build a world where they can shine and live their best lives.

And to do that… we have to keep the faith and keep doing hard things.