

EXTRAORDINARY PARENTING

Overcoming Optic Nerve Hypoplasia

Like some other newborn babies, Gentry Louise Hoffman exhibited a “fluttering” of the eyes or rapid eye movement called a nystagmus. This often stops once a baby is a few months old. But Gentry’s flutter still hadn’t gone away by the time she turned six months old. Her mom, Carolyn Hoffman, contacted Gentry’s pediatrician, who referred her to a pediatric ophthalmologist. That doctor diagnosed Gentry with optic nerve hypoplasia (ONH), a congenital condition present at birth characterized by the underdevelopment of optic nerves. It affects about one out of 10,000 children.

Gentry is now three years old and thriving thanks to the support of her family, her current pediatric ophthalmologist, and the Early Intervention program at Lighthouse of Manasota, a local nonprofit that works with blind and visually impaired residents in Sarasota, Manatee, DeSoto, Charlotte, and Highlands Counties. Carolyn shares with us what life is like for the Venice-based family—which also includes five-year-old Bristol Dare Hoffman and dad Trey Hoffman—and the impact early intervention has had on them.

What was it like for you as a parent, learning that your daughter has a visual impairment?

Learning Gentry had ONH was the worst day of my life. I don’t even remember hearing the words come out of the doctor’s mouth. I shut down. He was so nonchalant about it; it was like he was talking about the weather. For local families, I would *strongly* encourage heading a few more minutes north to Hess Pediatric Ophthalmology Specialists at Johns Hopkins All Children’s Hospital in St. Petersburg. Dr. Samantha Roland is who we see now, and I couldn’t adore her more. She’s truly the best of the best.

No parent wants to hear that something is wrong with their child. No parent wants to hear there is nothing that can be done for their child’s impairment. In my eyes, my child is perfect. How could this be happening to her? Then the guilt comes. What did I do that caused this? What did I do wrong while pregnant? What did I do to fail my child? The doctors always reassure me that it was nothing that I did, and that it’s just one of those things that happen. But the guilt never goes away.

I remember getting in the car after her diagnosis appointment and starting to feel it all, one emotion after another. My mind was racing, and I went from stone cold to tears streaming down my face to ugly crying. My worst fear had happened; something was wrong with my baby.

But every day gets easier. I watch her

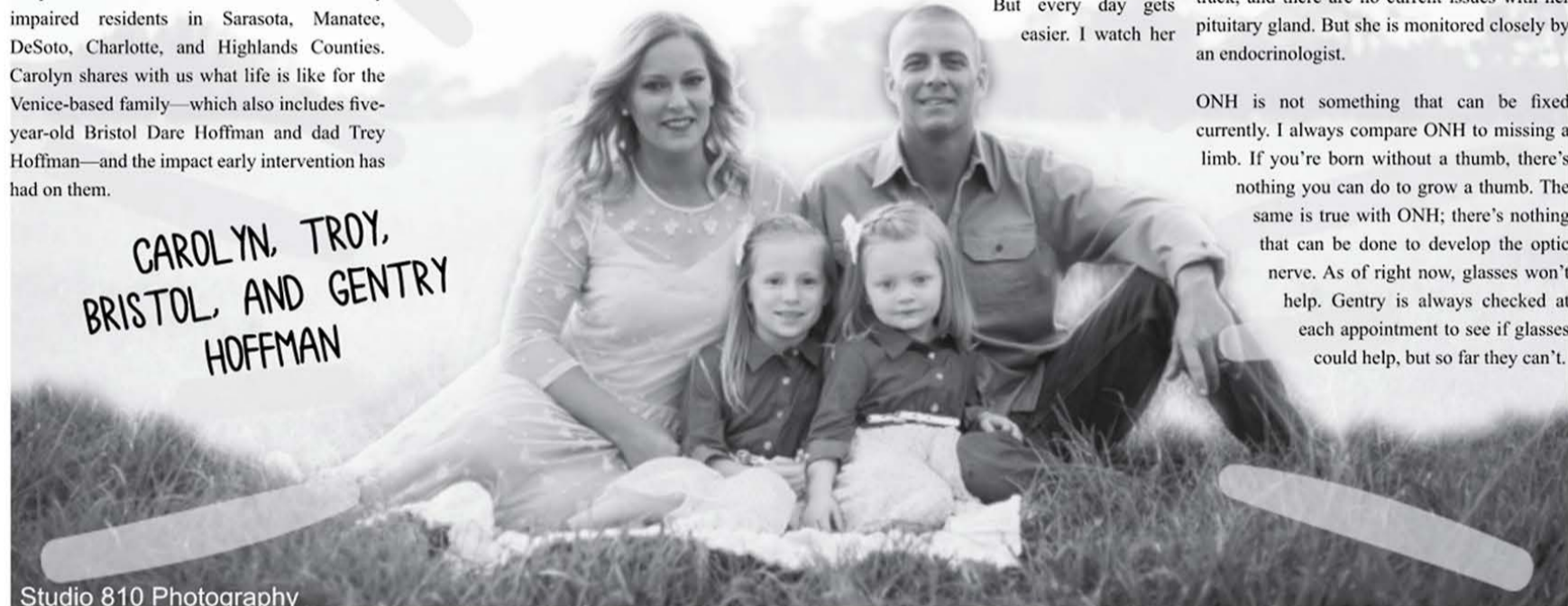
growing and thriving. I know that so many parents have it so much worse than we do, and I feel blessed that I was chosen to be her mommy.

From your point of view, what is life like for Gentry with ONH?

Gentry’s vision right now is 20/150. What a person with 20/20 vision can see at 150 feet away, Gentry can only see at 20 feet away. According to our pediatric ophthalmologist, she will not be able to drive. The development of the pituitary gland can also be affected in children with ONH. The pituitary gland is the body’s master control gland. It makes and directs hormones required for growth and other things. So far, Gentry’s growth is perfectly on track, and there are no current issues with her pituitary gland. But she is monitored closely by an endocrinologist.

ONH is not something that can be fixed currently. I always compare ONH to missing a limb. If you’re born without a thumb, there’s nothing you can do to grow a thumb. The same is true with ONH; there’s nothing that can be done to develop the optic nerve. As of right now, glasses won’t help. Gentry is always checked at each appointment to see if glasses could help, but so far they can’t.

CAROLYN, TROY, BRISTOL, AND GENTRY HOFFMAN



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What is day-to-day life like for your family?

Everyday life for us is totally normal. Well, as normal as life can be with a wild family like ours. If you didn’t notice Gentry’s nystagmus, you would never know her vision is impaired. She is even hitting milestones above her age range. If she is looking at something close up, sometimes she does have to get a little closer to it to see it, or she pulls it closer to her face. But she can see the moon out during the day. She can see rainbows and name every color in order. She can see bubbles.

Gentry is a little spitfire. She tells it like it is and doesn’t let anyone push her around. I’ve never met a more strong-willed child. I always used to say when Gentry was a baby, “Thank God she has a Bristol (her big sister) to take care of her.” And now we always say, “Thank God Bristol has a Gentry to take care of her.” She is funny, a free spirit, and dances like no one is watching. She is the absolute joy of my life.

Are there medical treatments that are part of your daughter’s everyday routine?

Right now we are seeing Dr. Roland once a year. There haven’t been any significant changes in Gentry’s vision since her initial diagnosis. One thing that she does do is she turns her head slightly to the right to steady the nystagmus. Turning her head steadies the fluttering, and she is able to see better. Her body has compensated for her impairment. Dr. Roland has said that she will probably need eye surgery within the next year or so to correct the head turn.



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Tell us about Lighthouse of Manasota and its impact on you and your daughter.

Gentry never crawled; she scooted. Her doctor recommended some occupational therapy from Early Steps. Early Steps is an amazing organization that specializes in early intervention. Gentry was seen by Karol Verdone, who was incredible. She worked with Gentry and had her walking within a month or so. Karol was the one who recommended Lighthouse of Manasota for vision therapy.

The first day Nancy Smith from Lighthouse of Manasota walked into our home, our lives changed. It felt like Gentry was the only child she saw, and she always gave her so much love, attention, and therapy. Gentry literally learns something new every time Nancy comes over. Nancy works with her in a way that feels like playing for Gentry, and she’s always so excited to see Miss Nancy. Nancy is super knowledgeable about ONH and is always a great support

system. She eases my fears and worries about Gentry’s impairment. We know what our doctors are telling us, but we also see how Gentry acts on a day-to-day basis. Nancy is passionate about the kids she sees and is truly incredible at her job. We couldn’t be more appreciative to have her in our lives.

Other resources or support systems?

Our family is a huge support system for us. We can talk openly about Gentry’s vision; it’s not a taboo subject for any of us. I feel better talking about it. I am so lucky to have friends and family we can talk to about her impairment, people who are there for me when I get sad about it and are there when we need them. When we see Gentry doing something that her vision should be holding her back from, we just look at each other and laugh. Social media has also given me the ability to connect with other parents of children with ONH. Hearing their stories and discussing our children is so helpful emotionally.

What is your advice to other parents out there who have a child with a visual impairment, especially for those who are maybe just starting out on a journey like your family’s?

Early intervention! Trust your gut; trust your instincts. If you think there may be an issue with your child, there probably is. No matter how big or small, talk to your doctors.

Take it day by day. Some days you’ll feel like your world is falling apart; other days you’ll realize how blessed you are. It’s hard when anything is wrong with your child, but always remind yourself that other parents are fighting much harder battles. Reach out for support. Talk to other families with children with the same issues. Love your child for who they are. I personally feel that Gentry’s disability has destined her for greatness. She will do amazing things with her magic eyes.

For more information about Lighthouse of Manasota, call 941-359-1404 or visit lighthouseofmanasota.org.

Beth Luberecki is a Venice-based freelance writer and editor and the mother of a 10-year-old. She writes about lifestyle, travel, and business topics for a variety of regional publications. To see more of her work, visit bethluberecki.com.

