

# HoPE News

Families for HoPE Newsletter



## FROM THE EXECUTIVE DIRECTOR

The romantic poet John Keats called autumn "season of mists and mellow fruitfulness." As I watch the leaves change from green to gold and welcome the crispness in the air, I am reminded of how wonderful this season can be. The kids are back in their classrooms again and we might find an extra moment or two to savor our morning coffee or walk down a quiet park path covered with fallen leaves.

This season is also a time to reflect on all we've accomplished in the past 8 months of the year and to consider our wishes and dreams for the remaining months ahead. Families for HoPE's accomplishments include continued growth fueled by all those who believe in our mission and support our vision in so many wonderful ways! These people, by sharing their stories, sponsoring a fundraiser, or giving their time and resources to us, continue to make it possible for us to *share the HoPE in holoprosencephaly*. It's a pleasure and privilege to recognize you and them in this issue.

As leaves dance on the wind in autumn's rich, golden hour, there's much still to do. I welcome you all to read about how you can join us in successfully wrapping up this pivotal year and preparing for 2024.

Wishing you a bright, mellow and cozy season,

*Susan*

Susan Millender  
Executive Director



## Newsletter Highlights

A Message of HoPE from the Executive Director

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Stetson's Story

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Thank you Sponsors and Families!

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Year End Fundraising

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2024 Family Conference on Holoprosencephaly



# STETSON'S STORY

WRITTEN BY CHANEL WILLIAMS



## KUDOS TO BRAINSKY LEVINSON!

We are sincerely grateful to our conference sponsor Brainsky Levinson for the awesome golf tournament fundraiser to ensure more HPE families benefit from our 2024 Family Conference. Thanks to all of the supporters!

## WE THANK YOU ALL!

Our summer t-shirt campaign - demonstrated that the t-shirt's action words reflecting our mission are all actions you all practice as much as preach! You helped us raise over \$2,000 to ensure we continue the important work FFH does daily.

## TRIBUTE GIFTS

Share your hope and show your admiration with a charitable gift to Families for HoPE in honor or in memory of a loved one. Visit [FamiliesforHoPE.org](https://FamiliesforHoPE.org) to make a secure, online donation.

From the beginning of Stetson's life to the end, it was unpredictable and rewarding all at the same time. Preparing for Stetson's delivery, we attended all prenatal checkups, received the 20-week anatomy scan, and any other testing that would check for birth defects. The day came to welcome our little guy, and nothing had indicated that we would otherwise be bringing home a healthy baby.

My scheduled C-section began and all was going smoothly until the doctor delivered Stetson. He said, "Baby has a cleft lip and palate we didn't know about." At that time, the OR erupted in panic. I knew something was wrong because I never heard him cry. I started panicking because all my questions about my baby were going unanswered. Shortly after he was born, Stetson was flown to our nearest children's hospital, 1 and a half hours from where he was delivered. I finally got to meet him 3 days later when I was discharged from the hospital. It wasn't until I arrived at the NICU that I realized we had almost lost him that day, and we still weren't out of the woods. He received a bedside tracheotomy in his NICU room because they couldn't get him stable enough to go to the OR. He had long, dark brown curly hair and a precious little face. He was nicknamed "Little Bear" because of this by his father, Bryan, and it just stuck with everyone.

It wasn't until about two weeks later, that we received his official diagnosis of Lobar Holoprosencephaly. I started doing my research because, like many others, I had never heard of this condition before. All the information I read and was being given by the NICU doctors was grim. "Not compatible with life" was all we were being told. I did not take that for an answer and continued my research. This is when I stumbled across the Families for HoPE Facebook page. I finally had hope for my little guy. I realized we were not alone on this journey and that we had a whole community of support behind us.

Stetson graduated from the NICU with a trach and a G-tube. After numerous hospital visits and upper respiratory infections, he would later require supplemental oxygen and a vent on CPAP settings to help manage secretions.

He had multiple other diagnoses, such as atrial septal defect, diabetes insipidus, and infantile spasms to name a few. Most days, you could find him watching Sesame Street or his Mickey Mouse-shaped light that danced across his bedroom ceiling. He loved hearing music and watching any type of multicolored lights. He was non-ambulatory and non-verbal, but that did not stop him from getting his way.



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## Stetson's Story continued

Stetson did not have to use words to let us know just how much he loved us or how thankful he was for us caring for him. He would look up at us with his big, blue eyes and give us the biggest grin. Just like most siblings, he enjoyed hearing his older brother, Casen, be corrected when he was behaving badly.

We celebrated all the milestones, from the big to the little ones. We threw him a Dr. Seuss "Oh the Places You'll Go" themed 6-month party. Every birthday was a blessing to us. We took him to his first Christmas parade to enjoy the lights and music because of Covid and the weather not cooperating we were never able to before. He usually watched from our bedroom window at home, but he got to attend this year. He sat in my lap and enjoyed every moment. We were unaware that just 12 days later he would be gone.

Stetson unexpectedly gained his angel wings on the night of December 15, 2021, at 4 years old. Our last family picture together was when we took him to see Santa. I will forever be thankful we decided to have them done. A couple of things I have learned from Stetson is to take the trip and make memories. Snap all the pictures because one day that will be all you have left. What I would do to be able to see his sweet smile, kiss his big cheeks one more time, and freeze that moment so it would last forever. Without Stetson, I wouldn't be who I am today. He made me more caring, understanding, and an advocate for the special needs community. My goal is for HPE to be talked about just like every other prenatal diagnosis, so once a family does receive their child's diagnosis, they already know that Families for HoPE exist. Thankfully, Families for HoPE and the online community has been there every step of the way.



The Williams family with Santa, left to right, Caden, Bryan, Chantel and Stetson.

## YEAR-END FUNDRAISING BEGINS

Here are some ways to get in on the action of year-end giving and *share the HoPE in holoprosencephaly to help raise \$50,000 by January 1, 2024:*

- **BUY** a Families for HoPE hoodie or long-sleeve t-shirt to keep warm and cozy while spreading awareness.
- **ENTER** the Costume Contest to show off your best Halloween creativity and share the fun photos of families and kiddos.
- **MAKE** a tribute gift in honor or in memory of a loved one.
- **ASK** people in your personal or business network who believe in our mission to match your year-end gift.
- **RALLY** your community, raise awareness and funds on National Make A Difference Day, October 28, 2023.
- **TELL** all on social media to give on GIVING TUESDAY, November 28, 2023.
- **HOST** a potluck harvest dinner or cocktail hour to tell guests about Families for HoPE and how meaningful their donations are.
- **DONATE** a drink for holoprosencephaly by giving up a daily drink and donating the money to support families instead.
- **INVITE** a local restaurant or bakery to donate a percentage of its sales to Families for HoPE on a given day. Then invite friends, family, colleagues to eat there.

## COME GROW YOUR HOPE GARDEN!

2024 Family Conference on Holoprosencephaly Provides Families Fertile Ground for Growth

The 2024 Family Conference on Holoprosencephaly convenes Sunday through Thursday, June 9th - 13th, at Great Wolf Lodge Hotel and Conference Center in Mason, Ohio. Since 2006, the biennial conference has provided an opportunity for families to connect, bond, share, learn and be supported. "No matter where we gather, families benefit from time spent together at the family conference," said Steve Harley, Board president, Families for HoPE. "We will learn from each other as much as we will learn from the medical professionals, financial planners, researchers, wellness practitioners and others. Families will have fun in a great setting, in the process of learning and practicing new skills together."


The four-day conference will feature a live music concert during its gala prom night, a day-long special outing for teen siblings, dads' networking night, moms' networking night, educational presentations and vendor fair. Families will hear from and engage with leading members of the medical community and other professionals, including grief counseling and support, family counseling, physical therapy, pediatric dentistry and more. Learn more and register at [www.familiesforhope.org/2024](http://www.familiesforhope.org/2024) family conference.




"THE 2024 CONFERENCE IS SURE TO BE ONE FOR THE AGES, AND WE ARE THRILLED TO BE RECEIVING SUCH GREAT SUPPORT FROM DONORS AND SPONSORS. WE DEEPLY APPRECIATE YOU ALL."

Steve Harley, Board President and 2024 Conference Committee Co-chair


## 2024 Family Conference - Get in on the Growth!




*Take a relaxing, stress-relieving and healing sound bath.*




*Meet other families and begin life-long friendships.*




*Meet with Certified Financial Planner Gordon Holmes who specializes in issues related to special needs.*



*Unwind, dine and enjoy the fun of socializing and celebrating together.*



*Consult with Dr. Nancy Clegg and the team from the Carter Centers for Brain Research on pressing concerns and questions.*



*Hear the news on genetic diagnosis from Dr. Paul Kruszka, GenDX, and updates from Dr. Seth Berger, Children's National, on gene environmental interactions and genetic causes of HPE.*