

WINTER, 2024

# HoPE News

Families for HoPE Newsletter



## FROM THE EXECUTIVE DIRECTOR

We're rapidly heading toward the end of another year. As the clock winds down to the close of 2024, I'm reflecting on the year's trials and triumphs. Did 2024 bring challenges? What year doesn't present its share of hurdles we must jump over? It is often those very trials that lead us to our biggest wins!

While we didn't convene an in-person Family Conference on Holoprosencephaly in 2024, we met with families from all over the world at our very first online, virtual conference in August. Some of the families who participated told us they had never before been able to benefit from attending a conference in person. All of the families who joined us said that the experience was educational and empowering.

Though we said goodbye to two valued board members, we welcomed three new members to the Board of Directors this year. During the year, board members both new and old made huge contributions to our mission to *empower, educate, support and advocate for all holoprosencephaly families*.

All of you played an important role in this year's success. You showed up on social media to share and care, encourage and inspire other families traveling along the roads of HPE. You gave and shared--time, talents, financial resources--to contribute to the strength of the HPE community we know and love. Through the trials and triumphs to come, may we continue to be *Better Together!*

Wishing you the happiest of holidays,

Susan Millender  
Executive Director



VOL.3, ISSUE 4

## Newsletter Highlights

A Message of HoPE from the Executive Director

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What Families for HoPE Means to HPE Families

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Holiday Humor

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Get Involved with Families for HoPE

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## HOPE FOR THE HOLIDAYS

The loss of a beloved child is often felt more strongly than ever, during the holidays. If you're a bereaved parent or family member of a child with HPE, we invite you to share thoughts and memories of that child. Talking or just sitting in solidarity with other bereaved families can help. We will gather each week on Wednesday from 9pm -10pm ET through January 3rd. Please consider joining us at [Zoom.com](https://www.zoom.us/j/89566510734) to give and to receive support. Meeting ID: 895 6651 0734 Meeting passcode: 203215

## 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.

## The Meaning of HoPE... Families Tell Us Why It Matters

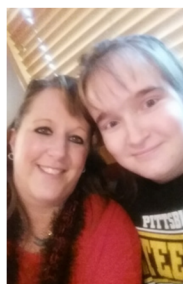
We asked members of our HPE community to tell us what Families for HoPE means to them. Here is what they told us:

*"When families are given a diagnosis of HPE, they are thrown into a world of unknown and given grim information based on statistics," said mom Chantel Williams. "Families for HoPE turns fear into strength by building a supportive community that helps navigate the challenging journey of HPE. HoPE becomes our guiding light, empowering families to overcome the challenges they face."*

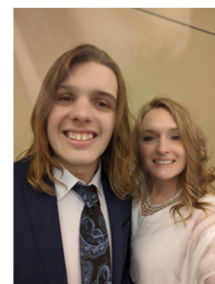
Dad Philip Brewer said, *"Families for HoPE started me in the right direction early on. I learned there are so many variances with HPE kids . . . it is not hopeless."*

*"It's hard to get anyone outside the (HPE) circle to understand the ups and downs and all the emotions that go with the uncertainty of your child's future," said mom Amy Rose. "But at Families for HoPE, they all understand."*

*"Children born with HPE are truly miracles," said mom Margie Wright. "Families for HoPE works to help the world realize and celebrate that fact every day."*



Amy Rose and daughter Marina



Margie Wright and son Kal-El

What matters most to Families for HoPE is what matters most to the families we serve. We are families, for families, by families--the only nonprofit peer-led family support organization for holoprosencephaly in the world. We are very grateful for the support of all those who engage with our organization and its families both online and in person. We couldn't do what we do without you.

## Anastasia's Mom remembers finding HoPE

*"I don't know where I'd be now, if it were not for other moms."*



Eight-year-old Anastasia Brant is making huge strides with her stander device at school and successfully using her communication device. Her mother Autumn Brant is focused on seeing her daughter stand and walk independently. Her strong belief in Anastasia's ability to reach that goal is grounded in hope.

Autumn was just nineteen, when she received a prenatal diagnosis of semi-lobar HPE. "I was immediately told to abort, though the doctor knew nothing about holoprosencephaly," Autumn says. "I went online to look up holoprosencephaly and find everything I could about it. That's how I found Families for HoPE and the Facebook group,"

"Families for HoPE has meant everything to us," says Autumn, "Going to a conference in 2022 gave me the chance to learn and to meet so many other families, see kids with the same diagnosis walking and talking." Autumn was positively impacted by meeting Ambassador for HoPE Brianna Bixenman. "Brianna is the same age as me, has HPE and is out there living her life!"

Autumn says she draws so much strength from other moms. "Reach out to the community," she advises all moms.

*"I can't help but be amazed by all of the HPE families. They continue to inspire me and fuel my passion for our mission."*

*-Steve Harley, President of the Board of Directors of Families for HoPE*

## HOLIDAY HUMOR - HO, HO, HO! Happy Holidays from Families for HoPE!

Don't blame the holidays,  
you were fat in August.

Dear Santa, it was my  
sister's fault.

Keep your friends close,  
your enemies closer and  
receipts for all major  
purchases!

Dear Santa, define nice.

Don't get your tinsel in a  
tangle!

Deck the halls and not your  
family. Fa la la la la



Happy Holidays! May your egg nog  
contain enough rum to get you  
through the season!

I never eat December snowflakes.  
I always wait until January.

I hope your smiles will be as big  
as your credit card bills this  
season.

Love the giver more than the gift.

I've learned that you can tell a lot  
about a person by the way they  
handle these three things: a rainy  
day, lost luggage and tangled  
Christmas tree lights.



# THANK YOU for Your GIFTS

## WE ARE GRATEFUL

As a community, we who have been touched by holoprosencephaly are still relatively small. Many people, including members of the medical community, have never heard of HPE. Thank you for raising awareness of this birth defect of the brain, and for raising funds to support our mission. Your gifts truly matter to children diagnosed with HPE, the families who love them, and the hope we ALL hold for their brightest future.

## YOUR GIFTS MAKE A DIFFERENCE

When you give to Families for HoPE, you ensure that your family and other families discovering our community for the first time find the support needed to survive and thrive along the journey with holoprosencephaly. Because of you, no family finds themselves alone and without needed support.

## NO AMOUNT IS TOO SMALL

Your gift in any amount is of great value to the families our mission serves. For as little as \$10, you help us remember the children we've lost and honor those who are still with us during every month of each year. A monthly donation of \$10 helps us welcome dozens of new families to our community each month. Thanks again for your gifts!



## Volunteer for Families for HoPE. . .

Are you social media savvy? Join us as a volunteer!

Are you an event organizer? We welcome you!

Is communications your strong suit? Tell us your story!

Are you an experienced fundraiser? Join us as a volunteer!

Does leadership come naturally to you? Get on board!

Are you a good facilitator? We need your support!

Interested in getting involved? If you're willing and able to help raise awareness of holoprosencephaly, please email us at [info@FamiliesforHoPE.org](mailto:info@FamiliesforHoPE.org)

