

HOPE News

Families for HoPE Newsletter



FROM THE EXECUTIVE DIRECTOR

I am totally enjoying my interactions with our HPE families on social media! Your posts and responses to mine really brightened up winter's long, dark days. Now that **spring** has sprung, your energy is fueling much creativity and great plans! Thanks to all of you who reached out in response to questions on FaceBook and our FFH website. I appreciate you for sharing your stories and for raising your hand in response to our call for volunteers. As you'll note in the letter from FFH Board President Steve Harley, **YOU** are what makes Families for HoPE great. There's nothing more important to me than centering our families, and elevating your interests, wishes and needs to the top of the FFH priority list. We are thrilled to receive your input and feedback and we will continue listening to you.

This issue of HoPE News reflects some of what we've heard from you. Well-being and connection matter to you in sharing encouragement and hope with others. Please keep sharing your thoughts and inspirations with us. Thanks so much!

Wishing you all a restorative spring,

Susan

Susan Millender
Executive Director



Newsletter Highlights

A Message of HoPE from the Executive Director

Self-care Benefits the Whole Family

A Letter from Board President Steve Harley

A Dad's Story of Hope

SELF-CARE BENEFITS THE WHOLE FAMILY

TIPS TO BOOST YOUR WELL-BEING

Prioritizing our own well-being helps us put our best foot forward as a parent

- Self-care creates calm, and calm can be contagious.
- Let your mind wander wherever it needs to go for a few minutes during the day.
- Breathe deeply between chores, meetings, doctors' appointments.
- Make the most of quiet time by sitting or doing simple tasks in complete silence.
- Take a 15-minute power nap.
- Meditate for just 10 minutes on a very busy day.
- Build time in your schedule for fun and play.
- Put down your phone.
- Eat more fruits and vegetables.
- Slow things down in the evenings to fall asleep more easily.
- Get outside to get more fresh air.



THANKS TO YOU . . .

with your generous support, Families for HoPE has received over \$11,000 in donations from our 2022 fall and year-end giving campaigns. We are truly grateful to all of donors, whose caring and generosity allow us to keep sharing the HoPE in holoprosencephaly.

Greetings Families,

My name is Steve Harley, and you may know me as Sammy Yammy's dad. Earlier this year, I was elected to serve as President of the Board of Directors of Families for HoPE, Inc., and I am excited to have begun my tenure on the cusp of a great change for our organization. I am leading a six-member board that is fully focused on growth and governance now to take Families for HoPE to new heights in the future, building on a 17-year legacy of successful family support, education, advocacy and resource sharing.



What does this change mean to you? In the coming months, you will begin to hear about new, exciting opportunities to connect and stay connected with us and our community of families touched by HPE. One such exciting opportunity is our **2024 Family Conference on Holoprosencephaly**. In 2024, the family conference returns to Great Wolf Lodge in Mason, OH. It's the same great location as 2018 and 2022--and a whole, new conference schedule and program to get families energized and engaged in growing a garden of hope! So save the dates June 10-13, 2024 and stay tuned for more information coming your way.

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A DAD'S STORY OF HOPE

A dad has special dreams of enjoying good times with his son – from pitching a baseball or playing hockey or walking the dog together to hitting the local skateboard park.

No dad envisions his son receiving a life-changing diagnosis or almost losing that beloved child twice. Philip Brewer's life with son Maddox started out with every wonderful expectation and anticipation of all the things a father and son have to look forward to doing together. Then, when Maddox was 4-months old, Philip and his former wife learned that their son had holoprosencephaly.



With that diagnosis, a dark chapter empty of hope began. "Men can feel especially alone," Philip says, reflecting on the low points in his journey with HPE. "Families for HoPE started me in the right direction early on, but the road has been dark and scary at times. You can always feel overwhelmed and lost at times. We went from no hope at that point of Maddox's diagnosis to reasons for hope through time." Through the connections and support given his family, Philip learned that there are so many variances with HPE kids. "Don't let the dire prognosis steal your hope," he says. "It is not hopeless."

Philip recalls the "darkest, scariest moment" of his life – Maddox's emergency intubation. The family held onto hope and saw their son survive. "The second time Maddox was intubated was for safety," says Phillip. Again, Maddox survived. Thankfully, doctors had learned that taking a pro-active approach produced hoped for life-saving results and new therapies to help Maddox.

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MEET UP ONLINE TO SHARE YOUR HOPE

Parenting a child with complex needs is both a challenge and a joy. As caregivers, parents need to carve out time for self-care and that includes time to socialize with other adults. If you're a dad who wants to connect with other dads, please join a FFH Dads Meet Up on Saturday, April 22nd at 4pm EDT on Zoom. Take 90 minutes to chat, laugh, unwind, relate and relax together with your peers. You can learn more about this Zoom event by joining the Facebook group for HPE dads named "Families for HoPE DADS".



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Today, Maddox is a "tween-ager" who will transition to a full-fledged teen in April when he turns 13 years-old. He is successfully co-parented by Philip and Maddox's mother Hailey, who lives nearby in their small town of Union City, Indiana adjacent to Richmond and Muncie, Indiana. Philip describes his son's personality as "bright." "He's always smiling," Philip says, even though he has his less-than-positive moments just like any other adolescent. Though non-verbal, Maddox is very much aware of his environment and everyone in it, his dad says.



On his family's journey with HPE, Philip has learned other key lessons. "Mental health is so important, especially during the winter months" he says, underscoring the importance of good self-care. Through his spiritual life encompassing prayer and God, Philip gains strength. Exercise, listening to music, playing guitar all contribute to Philip's self-care routine. "I love hiking, camping, and the desert," he says. "Music is something Maddox and I enjoy together, and I have learned to keep as rested as possible; I nap and sleep when he sleeps." Of course, Philip gives credit to having family and friends nearby, in addition to the help of a home nurse. "His nurse has been amazing and has been with us for almost 6 years now."

While Philip has been an active member of Families for HoPE's online dads group and attended a group outing in Indianapolis previously, he relishes and welcomes the opportunity for dads to get together regularly on virtual platforms like Zoom or Teams. He also welcomes in-person coffee chats and meet-ups for dads who live close to one another. "It's good to just connect, to laugh and joke on social media, Zoom or in person from time to time," he says. "Families connecting and holding the hope for one another makes us all stronger."

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Families for HoPE was created by families, for families and with families. That spirit is something that will always stay the same. While the Board and I busy ourselves with strategic planning, I want to empower and encourage you to reach out to us and let us know how Families for HoPE can help, how you want to get involved with us whether it be as a volunteer or as a liason between medical staff you encounter on a regular basis. We want to hear from you. What can Families for HoPE do better? How can we help? What ideas do you have for fundraising, education or our Facebook page and website? We really want to engage with our families more than we ever have before. Your lived experience is what inspires and fuels our mission.

I want to hear from you, so shoot me a message at steve.harley@FamiliesforHoPE.org.

With HoPE,
Steve Harley