

HoPE News

Families for HoPE Newsletter



FROM THE EXECUTIVE DIRECTOR

We're less than one month away from the mid-way mark of 2024. As each day winds its way to an ending and a new day begins, our busy lives continue to be filled with delights and demands, choices and challenges, grace and gratitude. . . and hope. Each day, we work to ensure a meaningful present and strive to build an even better future.

I've been thinking a lot about *legacy* - which the Oxford dictionary defines as *the long-lasting impact of particular events, actions etc. that took place in the past, or of a person's life*. Every life has meaning, we each impact the world we live in and others in our world. The impact we have as mothers and fathers is tremendous, in both our character and our actions. Saluting all moms and dads for the legacies you are building and wishing you each the very best!

Families for HoPE is also creating a legacy. For the past 18 years we've strived to advocate for, educate, empower and support families touched by HPE. Though weathering the storms of a changing world has presented many challenges, we have remained focused on our mission and steadfast in our commitment to families. Fortunately, we don't do this alone. We have special people to thank for their continued belief in our mission and their on-going support. We are thankful they have chosen to walk alongside of us. Expressing deepest gratitude to each of you.

Warmest wishes,

Susan Millender
Executive Director



Newsletter Highlights

A Message of HoPE from the Executive Director

Saluting Moms and Dads

Ambassadors for HoPE

Special Thanks to Special People

Families for HoPE - Making a Difference Every Day



SALUTING MOMS AND DADS. . .



HoPE for children diagnosed with HPE and their families inspire everything we do, as a 501(c)(3), nonprofit organization. Read more about our work on page 4.



YOUR LIMITLESS LOVE LIGHTS THE WORLD

*CELEBRATING YOU ALL AND WISHING EACH OF YOU
THE VERY BEST DAY EVER!*

You are the greatest teachers of love and compassion. You model courage, hard work, perseverance, and kindness. Your love is boundless and forever. You give selflessly and fully, only hoping to see those dearest to you grow and thrive. Your reward is their wellbeing, and you place their happiness above your own. You are moms and dads, otherwise known as the heroes and sheroes of your families. You stay in it to win it, even through the particularly overwhelming days, weeks, months and years. You embody hope. And your effort in parenting pays off in large ways and small.

You are the reason Families for HoPE exists. Parents like you started this support organization 18 years ago and parents like you are members of the Board of Directors, and other important groups that work to make a difference in the lives of families touched by holoprosencephaly today. As you celebrate your special day with family and friends, we want you to know that we're working to uncover more resources to support you in caregiving.

Parents of children with complex medical needs must also deal with many of the same challenges all parents face. Among these may be taking care of the mental health and emotional needs and security of the siblings of a child with HPE; sibling rivalry and constant fighting among siblings; feeling incompetent in your parenting skills or judged by others; your children's cybersecurity and online safety; sleep deprivation; balancing family and work; solo parenting; providing care for your own aging parents.

While we know there are no simple solutions to the issues parents face, there's a wealth of information to be shared in our online communities among those of you who are experiencing success dealing with some of the issues. We're excited to hear from you on Families for HoPE's social media platforms, encourage you to keep openly sharing in the safe, supportive and compassionate community we facilitate, and reach out to us to let us know your interests and how we can better serve them.

Families for HoPE's goal is to serve your needs in all ways possible - with information, resources, new programs and services based on your needs.

AMBASSADORS FOR HOPE

During the month of March 2024, Families for HoPE launched a new program and invited families to pilot the new program with us. The program is **Ambassadors for HoPE**.



Each of our inaugural families agreed to sign on for the next 12 to 14 months to raise awareness of HPE by telling their story; bringing hope to families by helping us expand our programs; helping to sustain Families for HoPE to ensure that we can bring hope to as many families as possible. This includes those with a prenatal diagnosis, newly diagnosed, and bereaved families.

We are grateful to the following people for launching the Ambassadors for HoPE program with us: Philip Brewer, Lauren Edwards, Stacy Jeanes, Hanna Jennings, and Jose and Gabby Pena.

We are looking forward to sharing more about Ambassadors for HoPE in our upcoming *Families First Podcast series*. Look for the series on our website www.familiesforhope.org.

In coming months, we look forward to inviting more families to the program. If you are interested in learning more about Ambassadors for HoPE, please email us at info@familiesforhope.org.



VOLUNTEERS, DONORS AND SPONSORS

We are so fortunate to have great people working with us to deliver our mission every day. This year's HPE Awareness Week benefited from volunteers who shared their ideas for celebrating a fun-filled week of activities.

Thank you to **Michelle Modula** and volunteers from Crossway Church for providing lovely greeting cards for our HPE families.

We continue to benefit greatly from the on-going support of donors. Our monthly donors are especially helpful in fueling our daily operations.

We are grateful for the conference sponsorship of **Brainsky Levinson LLC** and **SugarCreek**. We appreciate partnering with you again for a successful conference.

THANK YOU, Awareness Week Committee and Participants!

We thank all of you who have shared your inspirations and ideas, and participated in the celebration of HPE Awareness Week 2024 during the last week of March. Special thanks to **Leslie Harley, Andrea Curtis, Arika Gates, Chantel Williams, Nicole Podwys, Kamiron Self, Liana Dhimitri, and Avery Sanchez** for leading our Awareness Week 2024.

FAMILIES FOR HOPE MAKES A VITAL DIFFERENCE

“Oh my goodness!! I'm literally shaking and crying so much!! This year has been so, so rough and, I can't even put in words how extremely grateful we are for this!,” wrote the mom of a child diagnosed with HPE. This mom just learned her family has been awarded a scholarship to the 2024 Family Conference on Holoprosencephaly. Her family is just one of a collective 2,700 members of Families for HoPE and more than 3,500 followers on social media platforms. In the past year, Families for HoPE has welcomed more than 150 newly-diagnosed families to the HPE community.

For teenaged parents facing the daunting challenges of caring for a medically-fragile newborn with HPE, Families for HoPE provided a source of unwavering support and understanding. Recognizing the unique struggles they faced, we offered a safe space for them to share their fears and uncertainties, providing practical guidance and emotional reassurance every step of the way.

When a newly widowed father found himself grappling with the overwhelming responsibility of becoming the sole caregiver for his child with HPE after the passing of his spouse, Families for HoPE offered a compassionate ear and a comforting presence. We stood by his side, offering words of solace and encouragement as he navigated this difficult journey, ensuring he knew he was not alone.

In these and countless other instances, Families for HoPE remains steadfast in our commitment to providing personalized, compassionate support to families navigating the complexities of HPE. No matter the circumstance, we are here to offer a helping hand, a listening ear, and a shoulder to lean on.

While each family's journey is unique, the challenges they face and the emotions they experience are universal. It is through this shared experience that we find strength, compassion, and a sense of purpose. Together, we stand united in our mission to support, encourage, empower, educate and advocate for families whose lives have been touched by HPE.

We are thankful that families we serve stand with us in their commitment to support others. *“We HoPE to give back in the future to allow another family a chance when they are struggling!,”* wrote our family conference scholarship recipient. *“Oh my goodness!! THANK YOU!”*

YOU MAKE A DIFFERENCE WITH US. . .

Every day, your support of Families for HoPE matters through:

Your donations to Families for HoPE- *Each and every donation helps us continue to welcome new families and share the hope in holoprosencephaly with one another.*

Your sharing on Face Book and other Families for HoPE social media - The support you give to other parents encourages, educates and empowers them to continue to care for their kiddo with HPE, their families, and themselves.

Your volunteering for Families for HoPE - When you give the gift of your time, you offer endless possibilities for shaping the growth of our HPE community. Your creativity and hands-on work on special projects helps us continue to connect our families in fun ways.