

HoPE News

Families for HoPE Newsletter



FROM THE EXECUTIVE DIRECTOR

I am starting this fourth quarter of 2021 with HoPE. It is thrilling and a great honor to be the first Executive Director of an organization that is delivering such a vitally important mission - promoting awareness of HPE and providing hope to families with children with HPE. You, the parents, grandparents, sisters, brothers, aunts, uncles, family members and friends of these children are why I'm energized and excited, stepping into my new role. The strong bonds you've forged at conferences on Holoprosencephaly and the social media community you've created are great catalyst for the work I am now engaged in. I'm happy to join with you in working to grow and strengthen our organization and welcome more families to our community.

This is an auspicious time for my work to begin. Families for HoPE was built on a foundation of love, caring, compassion and connection. The strength of that foundation has been evident during the past 23 months of the coronavirus pandemic. HoPE persevered and prevailed. New families were welcomed. Programs and services continued, despite the challenges and destabilizing effects of a global health crisis. As 2021 draws to a close, we have much to look forward to, including the 2022 Family Conference on Holoprosencephaly, June 12th - 16th, in Mason, OH.

In the coming months, I look forward to listening to you and learning from you to understand your needs. I am confident that our organization, the only one of its kind, will continue to grow strong in its mission and vision.

Wishing you all Happy Holidays,

Susan Millender
Executive Director



Newsletter Highlights

A Message of HoPE from the Executive Director

Prioritizing Our Self Care

2022 Family Conference on Holoprosencephaly

Top Ten for HPE Parents



PARENTS' CORNER



THE HOLIDAY BLUES

Grief is hard work, and the holidays are especially hard for bereaved families.

That's why Families for HoPE invites you to join us for virtual meet ups on Zoom.com on Thursdays at 7pm Eastern Time. If you are grieving, please know that you are not alone; we can find hope together.

December 16, 23 and 30

Contact Leslie Harley at Leslie@FamiliesforHoPE.org to register and receive a Zoom link.



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 to make a secure, online donation.

PRIORITIZING SELF CARE

Taking care of the caregiver

Parents tend to place their children first, assigning lower priority to their own needs and wishes. As caregivers of special needs children, we experience unique stressors that demand extra doses of resourcefulness, stamina and resilience. Instructions to “make sure your oxygen mask is securely in place, before assisting others” can be especially important to heed, when we find ourselves overwhelmed and on the brink of exhaustion. In the midst of our constant efforts to proactively seek resources, support and advocate for our children, we may find ourselves frustrated, isolated and feeling such emotions as grief or anger. We have special needs of our own. Self care is one of those needs. Here are some ways we can begin to meet our needs:

Get Connected and Supported

Find others in our Families for HoPE community with whom you feel accepted, celebrated, safe and upheld. This could also mean joining a book club, strengthening your commitment to your faith community or taking a class that interests you.

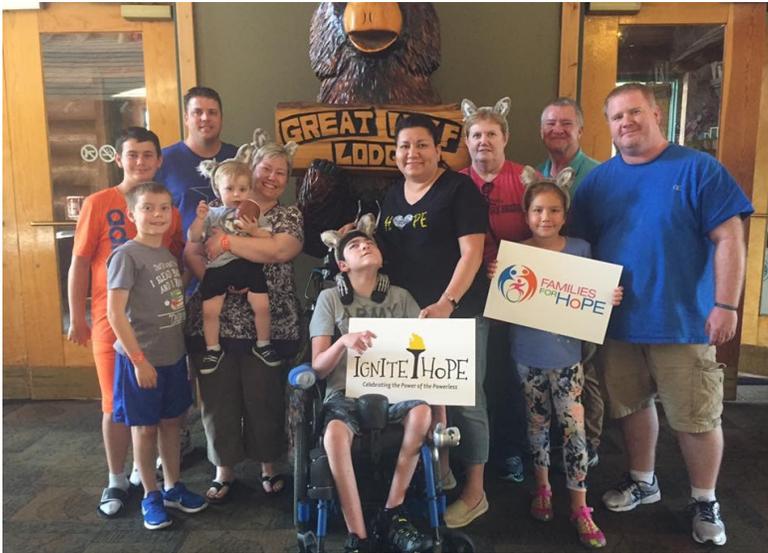
Seek and take advantage of respite care services in your city or state

Respite can help you replenish your emotional resources so you can be stronger and more resilient in your caregiving.

Meditate

Let go of endlessly regenerating thoughts, beliefs, fear-based stories and regrets and simply be mindful and present in our lives as it is right now. Meditation is one practice that allows us to slow down, be in the present moment, and let go of trying to fix or control external circumstances, even if only for 5 or 10 minutes a day. There are multiple phone apps available with free or low fee audio recordings of brief, guided meditations you can do between tasks, while you're waiting in line at the store, or when you're taking a bathroom break.

Remember our self care is a necessity and take time to prioritize the inclusion of at least one of the above practices in your life each day.



2022 FAMILY CONFERENCE ON HOLOPROSENCEPHALY

77 families registered to attend

The 2022 Family Conference on Holoprosencephaly will convene Sunday through Thursday, June 12th - 16th, at Great Wolf Lodge Conference Center and Hotel, Mason, OH. Since 2006, the biennial conference has provided an opportunity for families to connect, bond, share, learn and be supported. “We want to create good memories with and for each other,” said Leslie Harley, founding Board member and Treasurer, Families for HoPE. “We want dads to form bonds with other dads. We want siblings to see other children who look and act like their special brother or sister. We want moms to be pampered.”

Highlights of the four-day conference will be a career fair and day-long special outing for teen siblings, adult siblings' luncheon, dads' networking night, moms' networking night, educational presentations and vendor fair. The conference will also provide opportunities for parents and caregivers to hear from and engage with leading members of the medical community and other professionals in financial planning, grief counseling and support, family counseling, physical therapy, pediatric dentistry and more.

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Travel Insurance Helps Us Get Back to People and Places We Love



Planning to attend the 2022 Family Conference on Holoprosencephaly or taking a trip to visit friends and family in the new year? Travel insurance can provide benefits and coverage to protect you from unpredictable events. An internet search will reveal the wide variety of travel insurance types available to fit the unique needs of your family.

Base plans start as low as \$23 from companies such as Allianz and others.

You can purchase coverage that includes trip cancellation and interruption benefits, benefits for travel mishaps and emergency medical expenses, or expanded benefits that offer free coverage for children 17 and under traveling with a parent or grandparent.

2022 FAMILY CONFERENCE ON HOLOPROSENCEPHALY continued -

Conference presenters include Dr. Max Muenke, CEO, American College of Medical Genetics and Genomics; Dr. Seth Berger, medical geneticist at Children's National Hospital; Dr. Paul Kruszka, clinical geneticist and senior Vice President and chief medical officer at GeneDx,

Also among those scheduled to present at the conference are Dr. Michelle Christie, Director of neurophysiology with Texas Scottish Rite Hospital for Children; and Nancy Clegg, National HPE Project Director and Clinic Director at the Carter Centers for Brain Research in HPE. Cincinnati Children's Hospital Division of Developmental and Behavioral Pediatrics psychologist Dr. Kristn Curran will present on behavioral challenges in children with developmental disabilities.

Attendees will hear from Certified Financial Planner Gordon Homes; Clinical Dietician Janice Scott; Occupational Therapist Angela Shierk; and Research Occupational Therapist Heather Roberts.

Seventy-seven families have registered for the conference, as of this newsletter printing. Registration remains open through March 1, 2022. The registration fee is \$900 per family (includes lodging). Scholarships are available.

Contact Roxanne Steele at Roxanne@FamiliesforHoPE.org, (765) 977-1250 for more information, questions about registration or opportunities to be a sponsor of this impactful event.

"THE 2022 CONFERENCE IS COMING TOGETHER, AND WE ARE EXCITED TO SHARE THIS FAMILY-FRIENDLY, EDUCATIONAL AND SUPPORTIVE EVENT THAT FAMILIES FOR HOPE IS KNOWN FOR," SAID ROXANNE STEELE, BOARD SECRETARY AND CONFERENCE COMMITTEE CO-CHAIR.

LAUGHTER IS GOOD MEDICINE**Top 10 ways to tell that you're an HPE parent**

#10. At least one stuffed animal in your home has a DIY mic-key button.

#9. The toe of at least one of your shoes is embellished with a wheelchair tire tread mark.

#8. There's an IV pole in your living room.

#7. Within the first 24 hours of getting a new phone, you've added "holoprosencephaly" to your dictionary.

#6. You are on a first-name basis with the hospital parking garage cashier.

#5. You wear mittens in the winter so that you can secretly "flip the bird" at people who stare at your child.

#4. Your Christmas tree has a reindeer ornament made with pipe cleaners, googly eyes and a trach.

#3. You've spent at least one holiday in the PICU sleeping on a futon and dining on hospital cafeteria food.

#2. The word "stoma" is in your vocabulary.

#1. In the middle of the night as you're pulling wet sheets off the bed, you've uttered, "Damn, med port!"

