

SUMMER, 2023

HoPE News

Families for HoPE Newsletter



FROM THE EXECUTIVE DIRECTOR

I am welcoming the longer, warmer and lazier days ahead. Here's to summer--more time outdoors, the fun of holiday fireworks and picnics, days spent at the beach or in a lawn chair reading a book.

While you unwind, take time to listen to a segment of Families for HoPE's new podcast series *Families First!* The series, debuting in June, features interviews with FFH leadership and other interesting people with useful information for HPE families and all those who offer our families love and support.

June is a great starting point for you to begin planning for the 2024 Family Conference on Holoprosencephaly! Registration is open! Get a jump start on making next summer a joyful, inspirational, educational experience by registering NOW!

With summer, remember that "rest is not idleness and to lie sometimes on the grass under trees on a summer's day" is by no means a waste of time.

Wishing you all a safe and sunny summer,

Susan

Susan Millender
Executive Director



VOL. 2, ISSUE 2

Newsletter Highlights

A Message of HoPE from the Executive Director

2024 Family Conference Registration Is Open

Celebrating Grads & Dads

Families First Podcast Series Coming Soon!



BENEFITS OF ATTENDING THE FAMILY CONFERENCE

WHAT'S IN STORE FOR 2024

The Family Conference is about so much more than the location. The Family Conference is:

- A chance to network and learn with and from other parents.
- An opportunity to meet HPE researchers and ask questions about new developments.
- Time to learn new ways to practice self-care.
- Food, fellowship and fun for the whole family.
- Speakers and presentations on meaningful topics.
- Social gatherings for siblings of the child with HPE.
- A compassionate oasis for bereaved families.
- Nights out for moms and dads to enjoy themselves.
- A place to share your feedback and help plan for future family conferences.



2024 FAMILY CONFERENCE REGISTRATION IS NOW OPEN. . .

Get ready for a most rewarding experience. Register for the 2024 Family Conference on Holoprosencephaly today. Join HPE families from across the country and around the world on June 9 -12, 2024, at Great Wolf Lodge & Conference Center, Mason, Ohio.

The Family Conference on Holoprosencephaly is the premier event for families and persons who are affected by HPE, and their extended families and caregivers. We welcome those who have loved and lost someone affected by HPE and will have special sessions dedicated to bereavement topics. The 2024 conference will provide you with information you need to help you better manage the day-to-day life issues you and your family face when caring for or missing a child with HPE.

Siblings are invited and encouraged to attend! We will have special activities for siblings ages 13 and older which will include off-site field trips and more. Parents and other adult family members will enjoy many opportunities to renew acquaintances and make new connections with peers, during the family conference.

To register visit www.familiesforhope.org and complete the online registration. The registration fee is \$975 per family and includes all conference activities and 4-nights lodging.



Questions about the
2024 Family Conference
on Holoprosencephaly?

Please call
(888) 533-4443

or email
info@familiesforhope.org

Congratulations Class of 2023 Graduates

REACHING MILESTONES & CELEBRATING SUCCESSES

Meghan Musselman loves to learn, enjoyed school and, with the dedicated support of mom, dad, brother, grandparents and her peer helpers, teachers, and education aide at school, she mastered communicating with a speech device and *graduated*. "The best thing about Meghan isn't just everything she's overcome," says her mom Amanda Head. "It is that she has grown into such a remarkable young woman that she makes an impression on, and becomes the favorite of just about everybody!" Meghan, shown here on the night of her prom, developed her own way of communicating over the years, says her mom. "She has her own sign language and her own way of speaking. She is very expressive and quick to take note, with either pleasure or displeasure." Her mom added that Meghan's sense of humor and 'ability to catch sarcasm' is shown in her chuckles whenever someone says something snarky.



This lover of books and 80's rock music didn't hesitate to answer, when asked what her next goals would be, "More books, please," Meghan simply said.



Anthony Gonzalez also joined the ranks of recent grads, moving on from his old school and entering an adult day program with some friends. Mom Toni Mancino says Anthony loves to laugh and loves being around people. Anthony was born with a cleft lip and cleft palate that took three surgeries to repair. He also had a spinal fusion. Though he still struggles with endocrine issues, he loves to swim, enjoys watching animated movies, and possesses a zest for life that his mom fully supports. "I really am trying hard not to have him in the hospital always," she says. "I believe his quality of life means more than medical things that get in the way."

Both Meghan's and Anthony's accomplishments are testaments to the power of holding hope for our children touched by holoprosencephaly. Congratulations to these two youths and to all those who advocate for and support them. We celebrate them, every milestone reached, and all those still to come.

**CONGRATULATIONS TO ALL GRADUATES OF THE CLASS OF 2023!
WE ARE SO VERY PROUD OF YOU!**

Michael Bangit III
Anthony Gonzalez
Joshua Howard
Leah Faith Joyce

Amanda Musselman
Tyler Newlin
Timmy Short
Jack Wilson

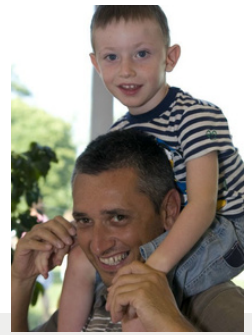
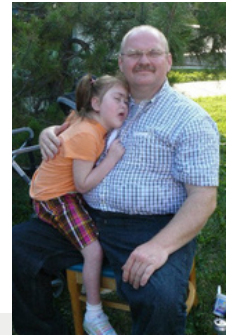

CLASS

OF
2023

HONORING ALL OF OUR AWESOME HPE DADS

Here are just a few of the things we always appreciate you for on any given day:

- Tender, loving support
- Great advice
- Fixing everything
- Dedication and reliability
- Integrity
- Grilled meat
- Good memories



"Being a dad is when you realize you can actually like people who puke in your car multiple times."

- Unknown



FAMILIES FIRST PODCASTS COMING SOON!



Something new is blossoming under the summer sun! Families for HoPE will launch a series of fun, informative podcasts at the end of June, 2023. "Podcasts are free, accessible, and always contemporary," says Families for HoPE Board President Steve Harley. "It's a great way for us to engage families and for families to stay informed."

Families First will present a broad array of people and subject matter, giving an up-close, personal, behind-the-scenes look into places and people throughout communities in which HPE families live, work and play.

Everyone, everywhere will be able to listen to segments via links posted on the Families for HoPE website and social media. Everyone is invited to join in the information-sharing and fun by sending us suggestions for topics of interest. Share your ideas by emailing info@familiesforhope.org.