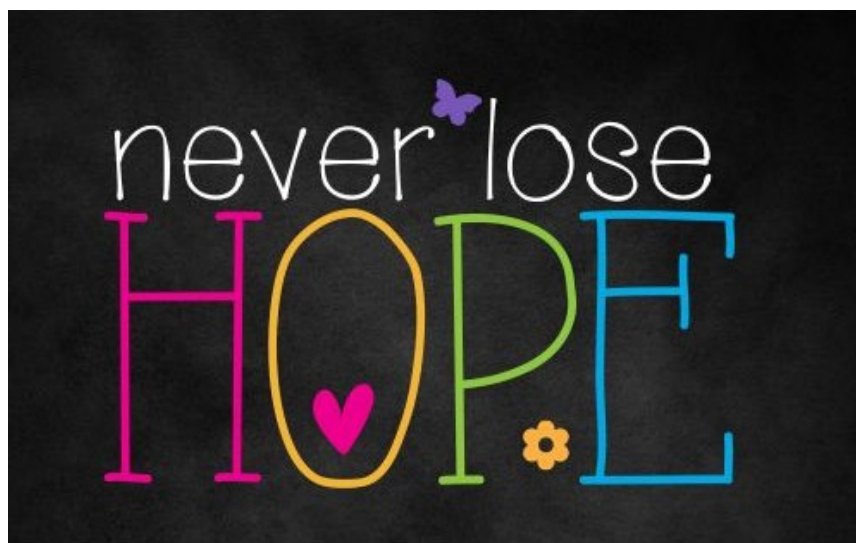


# Holoprosencephaly Awareness Week

## March 23 - 29, 2025

### Action Plan:

What you need to know for a fun and  
successful week



# THEMES

Each day has a theme

Sun, March 23 - HoPE happens

Mon, March 24 - Champions of HoPE

Tue, March 25 - Never lose HoPE

Wed, March 26 - Create HoPE

Thu, March 27 - HoPE teaches

Fri, March 28 - HoPE smells

Sat, March 29 - HoPE moves

In addition to a theme, each day has a suggested activity, a social media prompt and a graphic you can use on social media.

We suggest that you read the prompt and use it to help you compose an entry for your social media account. Before posting the entry, upload the graphic as a photo to go with your entry.

You may use any or all of the materials we have provided, and you may add your own photos, memes, information, etc. In addition, graphics from prior years' awareness weeks are available for downloading on [www.FamiliesforHoPE.org](http://www.FamiliesforHoPE.org)

There is a fundraising component if you should choose to participate to help raise funds for the programs and mission of Families for HoPE.

If you are interested in joining the Families for HoPE fundraising committee, please contact [Steve.Harley@FamiliesforHoPE.org](mailto:Steve.Harley@FamiliesforHoPE.org).

We also have opportunities for you and your family to become an Ambassador for HoPE for the organization.

## Fundraiser Info

Seeking a creative way to support Families for HoPE through the Ambassador for HoPE program, Indiana HPE moms Arika Gates and Leslie Harley turned to the popular trend of beaded pens to make a difference.

Under the banner of “all because of hope”, they set up booths at craft fairs and festivals, giving shoppers the opportunity to design their own ink pens, keychains, and other personalized items. Each item sold for \$10, not only helping to raise funds but also spreading awareness about HPE within their communities.



To celebrate HPE Awareness Week, we have designed a custom silicone focal bead with the “never lose HOPE” message. These focal beads along with other color-coordinating beads will be sold in DIY kits for making beaded pens, keychains and bracelets/wristlets. These items will be debuted and available for sale beginning on March 23, so check [FamiliesforHoPE.org](http://FamiliesforHoPE.org) on March 23 for more information.



The steps for you each day of the week:

1. Create a social media status update using the assigned prompt as inspiration.
2. Add that day's graphic as a photo for your status so it goes with the day's theme.
3. Encourage your family and friends on social media to help raise awareness of HPE.
4. If your family or child's classroom has participated in an activity for awareness week, please share that on social media as well.
5. Check out the DIY kits for sale at [www.FamiliesforHoPE.org](http://www.FamiliesforHoPE.org) to support our fundraising efforts.
6. Have a great week!





HOPE  
happens

The word 'HOPE' is written in large, colorful, outlined letters: 'H' is pink, 'O' is yellow with a pink heart inside, 'P' is green with a yellow flower inside, and 'E' is blue with a purple butterfly inside. Below it, the word 'happens' is written in a white, lowercase, cursive-style font.

## Holoprosencephaly Awareness Week

Sunday, March 23  
Day 1

HPE occurs in the earliest stages of pregnancy, between days 17-21 of fetal development. It happens during a crucial moment when the prosencephalon (forebrain) begins to separate, forming the left and right hemispheres of the brain. While HPE happens, so does hope—hope for strength, understanding, and a future filled with love and possibility. Hope happens.

To learn more about holoprosencephaly, visit [FamiliesforHoPE.org](http://FamiliesforHoPE.org)





## Holoprosencephaly Awareness Week

Sunday, March 23  
Day 1

**Social media prompt:** Use the “HoPE Happens” graphic and share on social media how HPE happened in your life. How did you receive the diagnosis?

**Activity:** In honor of Holoprosencephaly Awareness Week, we've created a limited-edition silicone bead, perfect for beaded pens, keychains, bracelets, and more. To make this even more special, we've designed DIY kits—offering a fun, hands-on activity and a meaningful way to support the programs of Families for HoPE. Order at [www.FamiliesforHoPE.org](http://www.FamiliesforHoPE.org)

 champions of 

HOPE

Holoprosencephaly  
Awareness Week

Monday, March 24  
Day 2

Every journey needs champions—those who stand beside us, lift us up, and bring hope into our lives. We want to honor the caregivers, supporters, and everyday heroes who make a difference for HPE families. If someone has been a Champion of HoPE in your life, send their name and mailing address to [info@familiesforhope.org](mailto:info@familiesforhope.org), and we will send them a special card to recognize their impact.

To learn more about holoprosencephaly, visit [FamiliesforHoPE.org](http://FamiliesforHoPE.org)



## Holoprosencephaly Awareness Week

Monday, March 24  
Day 2

Social media prompt: Who are the champions in your child's or family's life? What makes them a true Champion of HoPE? Share your stories and let's celebrate those who inspire us!

Classroom/school activity: Create and share medals of HoPE! Using ribbon, paper, aluminum foil, or other materials, design medals to celebrate the champions in your life. Give them to classmates, teachers, or friends who inspire and support you.

never lose  
HOPE

The word 'never' is in white lowercase letters, and 'lose' is in white lowercase letters. A small purple butterfly is perched on the dot of the 'i' in 'never'. The word 'HOPE' is in large, colorful, outlined capital letters: 'H' is pink, 'O' is yellow with a pink heart inside, 'P' is green, 'E' is blue with a small yellow flower at its base.

## Holoprosencephaly Awareness Week

Tuesday, March 25  
Day 3

The journey through HPE comes with many challenges—moments that feel like loss. The loss of dreams once envisioned, the loss of identity, the fading of relationships, or even the heartbreaking loss of a child. While loss is an undeniable part of life, it does not define the path ahead. Through love, resilience, and community, hope can be found again. Hold onto it. Never lose HoPE.

To learn more about holoprosencephaly, visit [FamiliesforHoPE.org](http://FamiliesforHoPE.org)



## Holoprosencephaly Awareness Week

Tuesday, March 25  
Day 3

**Social media prompt:** If you are comfortable with sharing, describe a time when you experienced a loss during your HPE journey. What has kept you from losing hope or how have you found hope again after loss?

**Classroom/school activity:** Give each student a strip of colorful paper and have them write or draw something that gives them hope—whether it's a person, a happy thought, a dream for the future, or something that makes them smile. Then, link the strips together to create a "HoPE Chain." As the chain grows, it becomes a visual reminder that hope connects us all and continues to grow when shared. Display it as a symbol of never losing HoPE!





## Holoprosencephaly Awareness Week

Wednesday, March 26  
Day 4

A diagnosis of HPE comes with a journey of learning –not only for families but for those around them. Many families find themselves becoming educators, helping others understand HPE and the unique experiences that come with it. Through sharing, we create awareness, foster understanding, and inspire compassion.

To learn more about holoprosencephaly, visit [FamiliesforHoPE.org](http://FamiliesforHoPE.org)



## Holoprosencephaly Awareness Week

Wednesday, March 26  
Day 4

**Social media prompt:** When someone is curious about your child or HPE, how do you approach their questions? Share a time when you or your child helped teach others about HPE or offered a meaningful lesson about life.

**Classroom/school activity:** Encourage students to reflect on and share something they've learned from a classmate—especially from a peer with different abilities. Discuss how these lessons help us grow in kindness, patience, and understanding. Because hope doesn't just inspire—it teaches.

**Family activity:** Watch an online demonstration on how to make items in the HPE Awareness bead kit.



HOPE  
smells 🧐

## Holoprosencephaly Awareness Week

Thursday, March 27  
Day 5

Did you know that years ago, it was widely believed that individuals with HPE could not experience the sense of smell due to the absence of olfactory bulbs. However, over time, HPE parents began noticing their children reacting to different scents –proving that hope, like scent, is something you don't always see but can certainly experience.

To learn more about holoprosencephaly, visit [FamiliesforHoPE.org](https://FamiliesforHoPE.org)



## Holoprosencephaly Awareness Week

Thursday, March 27  
Day 5

Social media prompt: Have you ever witnessed your child reacting to a scent? How did you discover they could smell? Share their favorite (or least favorite) scents and how these moments brought new understanding.

Classroom/school activity: Create and decorate silly paper noses to wear—because hope, like smell, brings unexpected joy!





## Holoprosencephaly Awareness Week

Friday, March 28  
Day 6

Life with HPE often calls for creativity—finding new ways to adapt, problem-solve, and bring joy into everyday moments. Whether it's designing a more accessible space, creating sensory-friendly activities, or finding unique ways to bring comfort and connection, hope is built through creativity.

To learn more about holoprosencephaly, visit [FamiliesforHoPE.org](http://FamiliesforHoPE.org)



## Holoprosencephaly Awareness Week

Friday, March 28  
Day 6

**Social media prompt:** Share a story about something you created, modified, or engineered to improve life for your child or family. How did your creativity help bring hope?

**Classroom/school activity:** Provide students with building blocks, craft supplies, or recycled materials and encourage them to create something that represents hope to them. It could be a structure, a piece of art, or a simple design that brings joy. Discuss how creativity helps us overcome challenges and build a brighter future!



HOPE  
moves

Holoprosencephaly  
Awareness Week

Saturday, March 29  
Day 7

Hope has the power to move hearts, inspire change, and impact lives—sometimes in the most unexpected ways. A small act of kindness, a shared story, or a simple moment of connection can create ripples of hope that reach far beyond what we can see.

To learn more about holoprosencephaly, visit [FamiliesforHoPE.org](http://FamiliesforHoPE.org)





## Holoprosencephaly Awareness Week

Saturday, March 29  
Day 7

**Social media prompt:** How has your child or your journey with HPE touched the hearts or lives of others? Share your story and invite your friends to reflect on how hope moves in their lives too.

**Family activity:** Take hope into action! Spend time in your community doing random acts of kindness—leave uplifting notes, donate items, help a neighbor, or simply share a smile. Hope moves when we choose to share it!