

Holoprosencephaly

Holoprosencephaly (HPE) (hol-o-pros-en-ceph-a-ly) is a birth anomaly in which the developing brain in very early pregnancy doesn't separate normally into separate left and right halves. This condition can also affect development of the head and face. Holoprosencephaly signs can include intellectual disability and problems with the brain's pituitary gland, which is a master control system for many hormones in the body. Holoprosencephaly can be caused by problems with genes, exposure of the mother to certain substances during pregnancy, or the cause can be unknown.

Resources for families

Northwest support resources

- Oregon Family to Family Health Information Center
tinyurl.com/y8ed6er5
- Washington Parent to Parent (P2P) Programs
tinyurl.com/yaucv2mk

National/international/online resources

- Fetal Health Foundation
tinyurl.com/y8bc5g2h
- Carter Database
tinyurl.com/y9ozo345

Family stories

- Teagan's Story
tinyurl.com/yadge9er
- Families for HoPE
tinyurl.com/y8yr5p5w

Clinical trial information

- Children and Clinical Studies
tinyurl.com/y75s4twm
- Find an approved clinical trial
tinyurl.com/zp3jesq

Insurance information and help

- Getting insurance for children (OR)
tinyurl.com/ydfaaeoy
- Getting insurance for children (WA)
tinyurl.com/yca9lkey
- Understand your health insurance
tinyurl.com/y46h8nvx
- Learn about coverage
tinyurl.com/y4639rz6
- Road map to health
tinyurl.com/yysc6kv7
- General/Oregon Health Plan Questions:
855-323-6744

Other resources

- My Face
tinyurl.com/ybl49wh9
- Complex Child magazine
complexchild.org

Books for parents and children

- Bibliography available by calling the Oregon Family to Family Health Information Center at 855-323-6744
- Swindells' online library search
tinyurl.com/y9t2jwcx