



# 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](https://tinyurl.com/y8ed6er5)
- Washington Parent to Parent (P2P) Programs  
[tinyurl.com/yaucv2mk](https://tinyurl.com/yaucv2mk)

### National/international/online resources

- Fetal Health Foundation  
[tinyurl.com/y8bc5g2h](https://tinyurl.com/y8bc5g2h)
- Carter Database  
[tinyurl.com/y9ozo345](https://tinyurl.com/y9ozo345)

### Family stories

- Teagan's Story  
[tinyurl.com/yadge9er](https://tinyurl.com/yadge9er)
- Families for HoPE  
[tinyurl.com/y8yr5p5w](https://tinyurl.com/y8yr5p5w)

### Clinical trial information

- Children and Clinical Studies  
[tinyurl.com/y75s4twm](https://tinyurl.com/y75s4twm)
- Find an approved clinical trial  
[tinyurl.com/zp3jesq](https://tinyurl.com/zp3jesq)

### Insurance information and help

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

### Other resources

- My Face  
[tinyurl.com/ybl49wh9](https://tinyurl.com/ybl49wh9)
- Complex Child magazine  
[complexchild.org](https://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](https://tinyurl.com/y9t2jwcx)