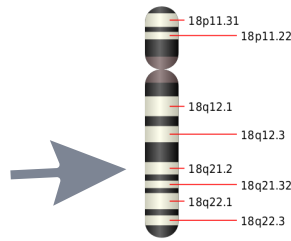




PITT HOPKINS SYNDROME

Pitt Hopkins Syndrome (PHS) is a rare neurodevelopmental disorder caused by a mutation of the TCF4 gene on the 18th chromosome.



The TCF4 gene plays an essential role in the development of the nervous system and the brain.

Characteristics

breathing problems:
hyperventilation, apnea
& breath-holding 25%



lack of speech:
nonverbal
pre-verbal/AAC users



gastrointestinal issues:
low motility, gas &
constipation 76%



compromised gross motor:
motor coordination (ataxia),
or nonmobile



short attention span
sensory processing disorder
anxiety



developmental delay
seizures/epilepsy 24%



vision impairment:
• strabismus or exotropia
• myopia 80%



compromised fine motor
skills



feeding challenges:
oral aversions & aspiration



- How they learn -

Give them time to process requests. Need repetition to build neuro pathways.
Highly attracted to sensory rich environments (music, lights).
Always presume competence.

Affects
approximately
between
1 in 34,000 and
1 in 41,000



Affects both genders
and all races equally.

- Treatments -

There is currently **no cure** for Pitt Hopkins syndrome.

However, treatment services can help people learn important skills.

Services can include therapy to learn to walk, communicate and have improved fine motor skills. The PHRF is funding promising research to find treatments and an eventual cure for PTHS, which you can read about at

pitthopkins.org/research

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INFORMATION & DONATING TO RESEARCH.

FIND OUT MORE



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