

Overview of important information about Wolf-Hirschhorn syndrome

Each individual with Wolf-Hirschhorn syndrome is unique. Most individuals with Wolf-Hirschhorn syndrome have some degree of development and intellectual delay, and are anywhere from mildly to severely affected. Other possible health concerns include hearing loss, abnormalities in the heart, eyes, brain, skeleton, and urinary system, and seizures (which generally go away with age).

What is life like for people with Wolf-Hirschhorn syndrome?

People with Wolf-Hirschhorn syndrome can have loving relationships with friends and family, and learn and make progress in their social skills and communication at their own pace. Most individuals with Wolf-Hirschhorn syndrome will need support and care over their lifetime given the related medical issues.

What causes Wolf-Hirschhorn syndrome?

Wolf-Hirschhorn syndrome is caused by a deletion on the short arm (p) of chromosome 4. The symptoms of Wolf-Hirschhorn syndrome are believed to be caused by the loss of multiple genes on this chromosome due to the deletion. Most of the time (85-90%), this deletion is said to be 'de novo', which means that it was not passed down from a parent; it is brand new in the individual who is diagnosed with the condition. In this case, the deletion occurs in the development of an egg or a sperm and is then copied over into every cell in the developing baby's body.

In some cases, Wolf-Hirschhorn syndrome can result from a genetic change causing chromosome 4 to become a ring chromosome. A ring chromosome is created when a chromosome breaks at both ends and the two ends fuse to form a circle. The loss of genetic material when this happens can cause Wolf-Hirschhorn syndrome.

In other cases, Wolf-Hirschhorn syndrome can be inherited when one parent's chromosome 4 is part of a balanced translocation. A balanced translocation is when a piece of chromosome 4 breaks off and trades places with a piece of another chromosome. No genetic material is lost when this happens, the chromosome pieces just trade places. Because the parent has not lost any genetic material, they do not show symptoms for any genetic condition. However, when they have children, their egg or sperm can be missing genetic material from chromosome 4 leading to a higher chance of Wolf-Hirschhorn.

What are the health and developmental concerns associated with Wolf-Hirschhorn syndrome?

Wolf-Hirschhorn syndrome is associated with a variety of health and developmental concerns, including:

- small head size (microcephaly)
- low birth weight
- delayed growth
- low muscle tone (hypotonia)
- distinctive facial features (called a “Greek warrior helmet”)
- most tend to be shorter than average due to delayed growth
- very delayed development of motor skills like sitting, standing, and walking
- delayed or absent speech
- mild to severe intellectual disability
- scoliosis
- hearing loss
- seizures
- some may be born with abnormalities in the heart, eyes, brain, skeleton, and urinary system

The severity of symptoms may be related to the amount of genetic material missing from chromosome 4.

If I have a baby with Wolf-Hirschhorn syndrome, what is the chance I will have another baby with this condition?

Because most cases (85-90%) of Wolf-Hirschhorn syndrome are caused by a de novo deletion on chromosome 4, there is not expected to be a high chance of having another child with it. However, if the deletion occurred early enough to be present in more than one egg or sperm, there could be a slight increased risk to have another child with the condition.

If Wolf-Hirschhorn syndrome was inherited from a parent with a chromosome 4 translocation, the chance of having another child with it depends upon the specific pieces of chromosomes exchanged. If you are found to have a chromosome translocation, meeting with a specialist, such as a genetic counselor, can help to better understand what your specific risks may be.

How do parents of children with Wolf-Hirschhorn syndrome feel about raising a child with it?

Many families of children with Wolf-Hirschhorn share valuable information and support with each other through the wolfhirschhorn.org. Their [web site](http://wolfhirschhorn.org) has lots of helpful information for families with a member who has Wolf-Hirschhorn syndrome.

What is the treatment for Wolf-Hirschhorn syndrome?

There is no cure for Wolf-Hirschhorn syndrome. However, medical management and therapeutic intervention can help individuals reach their full potential. Individuals with Wolf-Hirschhorn syndrome will require regular follow-up and treatment by a variety of health specialists to treat their specific needs. Intervention programs such as physical therapy, special education, speech therapy, and occupational therapy can be beneficial to individuals with Wolf-Hirschhorn syndrome. Basic health care recommendations are available on 4p-supportgroup.org/.

What are the long-term outcomes for individuals with Wolf-Hirschhorn syndrome?

It is important to recognize that the health and developmental effects of Wolf-Hirschhorn syndrome vary from person to person. Speech and mobility issues can be improved with intervention programs. Individuals with Wolf-Hirschhorn syndrome may have moderate to severe intellectual disabilities, and may benefit from special education. Medicine can also be used to manage seizures. Most individuals with Wolf-Hirschhorn syndrome will need support and care over their lifetime given their health and developmental concerns. Life expectancy is unknown for individuals with Wolf-Hirschhorn syndrome, but some individuals have lived into their 40's.

How common is Wolf-Hirschhorn syndrome?

Wolf-Hirschhorn syndrome is believed to affect between 1 in 20,000 and 1 in 50,000 people.

Click [here](#) to learn more about scheduling a genetic counseling appointment for pregnancy-related questions.

Click [here](#) to learn more about scheduling a genetic counseling appointment for infertility or preconception questions.

Click [here](#) to learn more about scheduling a genetic counseling appointment for questions

about pediatric or adult genetic conditions.

Resources

[4P Support Group](#)

wolfhirschhorn.org