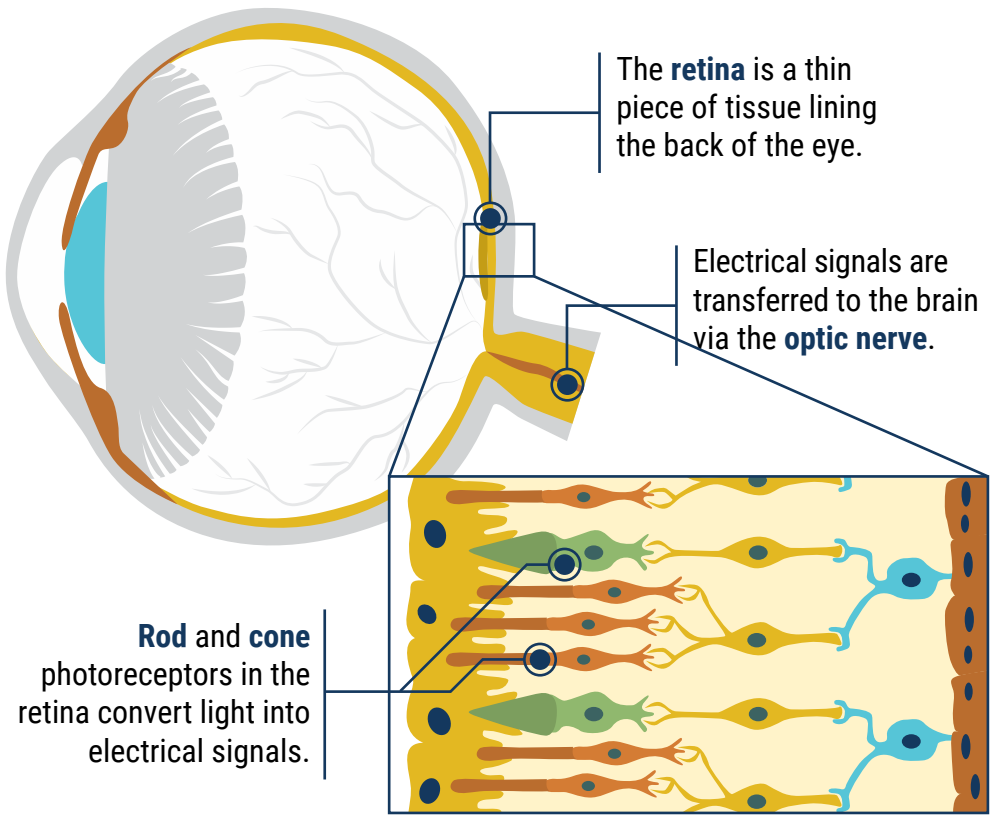
WHAT YOU SHOULD KNOW ABOUT

BARDET-BIEDL SYNDROME

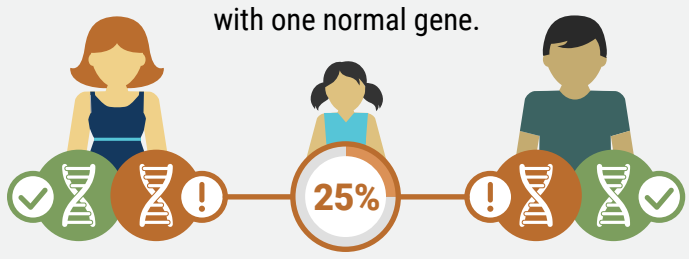
WHAT IS BARDET-BIEDL SYNDROME (BBS)?

Often diagnosed in childhood or adolescence, BBS is an inherited disease causing progressive loss of night and peripheral vision from retinitis pigmentosa (RP).



HOW IS BBS INHERITED?

Bardet-Biedl syndrome is autosomal recessive. That means it is **genetically passed** when both parents have one gene for the syndrome paired with one normal gene.



There is a **25% chance** of their child inheriting the two BBS genes. **18 BBS causing genes** have been identified.

GENETIC TESTING

Genetic testing helps with attaining an accurate diagnosis. It also helps assess the risk of passing the disorder to offspring. A patient with an accurate diagnosis is in a better position to understand which emerging treatment approaches and clinical trials are most appropriate for them.

People with BBS-related RP experience a gradual decline in their vision, because photoreceptors degenerate.

WHAT TO EXPECT WITH BARDET-BIEDL SYNDROME:

The diagnosis of Bardet-Biedl syndrome is often made at birth or in childhood when problems due to retinitis pigmentosa or other problems related to the syndrome are discovered.

VISION RELATED SYMPTOMS:

Night Blindness

Loss of Peripheral Vision

Central Vision Loss

OTHER RELATED SYMPTOMS:

Symptoms vary from person to person.

Polydactyly
Extra fingers and toes are usually removed in infancy or early childhood.

Obesity
May be present by childhood and is usually limited to the trunk of the body.

Developmental Disabilities
Mild impairment, delayed emotional development, or intellectual disability.

Renal (Kidney) Disease
Renal abnormalities can affect the structure and the function of the kidneys.

FOUNDATION FIGHTING BLINDNESS

To learn more about living with Bardet-Biedl syndrome, finding a specialist, genetic testing or clinical trials, visit **FightingBlindness.org** or call **888-332-3667**.