

USHER SYNDROME

A GENETIC DIAGNOSIS THAT AFFECTS HEARING, VISION, AND BALANCE



hearing

hearing differences may be present from birth, or may develop gradually over time; hearing levels can range from mild to profound



vision

progressive vision loss is caused by retinitis pigmentosa (RP), which begins with night blindness



balance

certain types of Usher syndrome cause balance issues

TYPES OF USHER SYNDROME

TYPE 1

- Profound deafness from birth
- Decreased night vision before age 10
- Balance challenges from birth

TYPE 2

- Moderate to severe hearing loss from birth
- Night vision challenges begin in late adolescence
- Normal balance

TYPE 3

- Typical hearing at birth with progressive changes in childhood or teen years
- Vision varies in severity; night vision challenges begin in teen years
- Possible late onset balance challenges



approximately
20,000 - 50,000
individuals living
with Usher
syndrome in the US

WHAT CAUSES USHER SYNDROME?



Usher syndrome is a genetic disorder, meaning it is passed from parent to child. A child is born with Usher syndrome when they receive a copy of the gene from both parents.



Both parents must be a carrier of the Usher gene. Carriers of the gene are often unaware since they have typical hearing and vision. Only genetic testing can confirm the presence of the Usher syndrome gene.

USHER SYNDROME
AWARENESS DAY
EVERY THIRD SATURDAY
OF SEPTEMBER

USHER SYNDROME ACCESSIBILITY IN EDUCATION

Accessibility services for individuals with Usher syndrome vary based on the degree of hearing and vision loss, meaning accommodations look different for everyone! Some suggested accommodations are:

- Accessible handouts
 - large font, clear visuals, etc.
- Good lighting; no glares
- Environmental descriptions
- Sign language interpreters
- Closed Captioning
- Reduced background noise
- Paraprofessionals
- Accessible technology for remote instruction
- Frequent check-in for understanding
- Reflective tape for entrances and stairs
- Copies of materials

TREATMENT

Currently, there is no cure or treatment for Usher syndrome, but there are treatment options currently being **studied** to determine their efficacy. These include:

- **Gene therapy**
- **Stem cell therapy**
- **Retinal implants**
- **Drug-based therapy**

Organizations like the Usher Syndrome Coalition are constantly working to better understand Usher Syndrome, improve quality of life for individuals with the disorder, and find new treatments for the vision, hearing, and balance issues associated with the disorder.



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**ABOUT USHER
SYNDROME
COALITION**



**USHER
SYNDROME FAQs**



**ADDITIONAL USHER
SYNDROME
INFOGRAPHIC**



**SUGGESTED
ACCOMMODATIONS**



**USHER SYNDROME
IEP CHECKLIST**

