

TALKS

If you believe that you and your healthcare professional colleagues would find value in a presentation or talk on Usher syndrome and strategies for establishing a more inclusive environment to effectively assist patients with USH, please feel free to reach out for further details.

SUPPORT

Receiving a diagnosis of Usher syndrome can be overwhelming for individuals and families. It's crucial to offer reassurance that they **are not alone** and to provide them with our contact information. We are dedicated to offering information, support, and connections to an understanding community.

MORE INFORMATION

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HCP Leaflet



Usher Syndrome Ireland

Together we can bring hope for
sight and sound

WHAT IS USHER SYNDROME?

Usher syndrome (USH) is a rare genetic condition characterised by bilateral sensorineural hearing loss (SNHL) combined with retinitis pigmentosa (RP). RP is a gradual eye disorder that affects the photoreceptor cells in the retina, resulting in night blindness and tunnel vision. Additionally, certain individuals with USH may experience vestibular challenges. You can learn more about Usher syndrome in our dedicated HCP section on our website: www.usherireland.org



USH is genetically inherited in an autosomal recessive manner. Genetic testing is advised when a patient presents with bilateral SNHL and symptoms of RP. Currently, there are 12 recognised genes associated with USH.

TYPES AND SUBTYPES OF USHER SYNDROME

- **Usher syndrome type 1**
USH1B USH1C USH1D USH1F USH1G USH1J
- **Usher syndrome type 2**
USH2A USH2C USH2D
- **Usher syndrome type 3**
USH3A USH3B
- **Usher syndrome type 4**
USH4

HOW COMMON IS USHER SYNDROME?

The prevalence of Usher syndrome within the general population ranges from 3-10 individuals per 100,000, comprising 3%-6% of all deaf children. In Ireland, it is estimated that around 250 individuals may be affected by USH.



The onset and severity of the symptoms associated with USH can vary among individuals, even within the same USH subtype.

This can make it challenging to predict various aspects of the condition such as, when sight loss might occur, if hearing loss will be progressive, and the extent of sensory impairment at a specific age

Therefore, it's important to advise patients to maintain regular contact with their ophthalmologist and audiologist to monitor any changes in both vision and hearing.

ABOUT US

We are a non-profit, patient-led volunteer organisation established in 2021 with a clear mission to:

- ③ Provide support and reliable information to individuals, families, and healthcare professionals.
- ③ Advocate and increase awareness.
- ③ Allocate funding for USH research.