

RESEARCH

Presently, there is no cure or treatment for Usher syndrome but, research is advancing rapidly. **As part of our mission**, we raise funds for global Usher syndrome research and provide the latest research updates on our digital platforms.

SUPPORT

Receiving an Usher syndrome diagnosis can be devastating. We want to reassure you: **you are not alone**. We're here to provide information, support, and connections to a understanding community. Please reach out to us for more details and advice.



MORE INFORMATION

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Usher Syndrome Ireland

Together we can bring hope for
sight and sound



WHAT IS USHER SYNDROME?

Usher syndrome (USH) is a rare genetic condition causing hearing loss and a slow progressive loss of sight. Some people with Usher syndrome have balance issues too.

There are four types of Usher syndrome which is inherited when **both** parents have passed the same USH gene to their child.

To learn more about Usher syndrome, its types and subtypes, genes, research, and more, go to:
www.usherireland.org

Retinitis Pigmentosa (RP), a component of Usher syndrome, is a progressive condition that leads to vision loss. This eye disorder impacts the light-sensitive cells within the retina, resulting in gradual vision impairment characterised by night-blindness and tunnel vision.

TYPES & 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?

Usher syndrome is very rare. It is estimated that over 400,000 people worldwide may have Usher syndrome with approximately 250 people in Ireland having this condition.

Usher syndrome affects each person differently as the symptoms can vary from person to person, even for those with the same USH type. This makes it difficult for professionals to predict various aspects of the condition, such as the timing of sight loss onset, the rate of progression, potential worsening of mild hearing loss, and the extent of sensory impairment at specific ages.

Therefore, it is important to maintain regular appointments with your 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.