

RESEARCH

While currently, there's no cure/treatment for Usher syndrome, research is moving at a fast pace.

As part of our mission, we raise funds to go towards global Usher syndrome research, and regularly share up-to-date research news.

SUPPORT

Receiving an Usher syndrome diagnosis can feel devastating. We want to reassure you, **you are not alone**. We are part of a large and supportive USH community who are here to listen and support. Please reach out to us for more information.

MORE INFORMATION

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Usher Syndrome Ireland

Together we can bring hope for sight and sound



WHAT IS USHER SYNDROME?

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

There are four major types of Usher syndrome which is inherited when **both** parents have passed an USH gene to their child. You can learn more about Usher syndrome, each of the USH types, USH genes, research, and much more, on:

www.usherireland.org

TYPES OF USHER SYNDROME

- **Usher syndrome type 1**
USH1B USH1C USH1D USH1F USH1G
- **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 onset and severity of the symptoms can vary from person to person, even for those with the same USH type. This can make it difficult for professionals to predict when sight loss may begin, how slow/fast it will progress, whether hearing loss will be progressive for those with a milder loss, and how severe they may be by a certain age.

Therefore, it's important to maintain regular appointments with your ophthalmologist and audiologist to track any changes in both vision and hearing.

Retinitis pigmentosa, also known as RP, is an eye disorder affecting the light-sensitive cells in the retina. It causes the vision loss as part of Usher syndrome, leading to night-blindness and tunnel vision.



ABOUT US

We are a non-profit volunteer organisation set up in 2021 with the mission to support, advocate, and fund global research into this condition.