TALKS

If you feel you and your HCP peers would benefit from a presentation/ talk to learn about Usher syndrome and how to create a more accessible environment to best support patients with USH, please get in touch for more information.

SUPPORT

Receiving an Usher syndrome diagnosis can be devastating. It is important to reassure patients with USH, **they are not alone**. We provide information, support, and an understanding community for all those affected by this condition.

MORE INFORMATION

15 Windsor Terrace, Co. Dublin,
A96 RF29, Ireland
+353 89 262 4696
contact@usherireland.org
www.usherireland.org

Usher Syndrome Ireland

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 disease causing hearing loss (HL) combined with retinitis pigmentosa (RP). RP is an eye disorder affecting the photoreceptors cells in the retina leading to night-blindness and tunnel vision. Some USH patients also experience vestibular issues.

USH is genetically inherited in an autosomal recessive manner. You can learn much more about Usher syndrome in our HCP section on our website: **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?

The prevalence of USH in a general population varies between 3-10 people per 100,000 and accounts for 3%-6% of all deaf children. In Ireland, it's estimated about 250 people may have USH.

The onset and severity of the symptoms associated with USH can vary for each person, even for those with the same USH genetic mutation.

This can make it difficult to predict the onset of sight loss, how it will progress, whether hearing loss is progressive for those with a milder loss, and how severe the loss of each sense may be by a certain age.

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

Genetic testing is advised when a patient presents with HL and symptoms of RP. Currently there are 12 identified causative USH genes.

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.