RESEARCH

Currently, there is no cure or treatment for Usher syndrome, but research is making progress. Through generous donations, we support global Usher syndrome research. We also provide research updates on our website, social media channels, and in our monthly newsletter.

SUPPORT

An Usher syndrome diagnosis can be overwhelming, but **you are not alone**. We offer information, support, and connections to a community that understands. Additional support and connections can be found at our yearly in-person event for individuals and families affected by Usher syndrome.

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

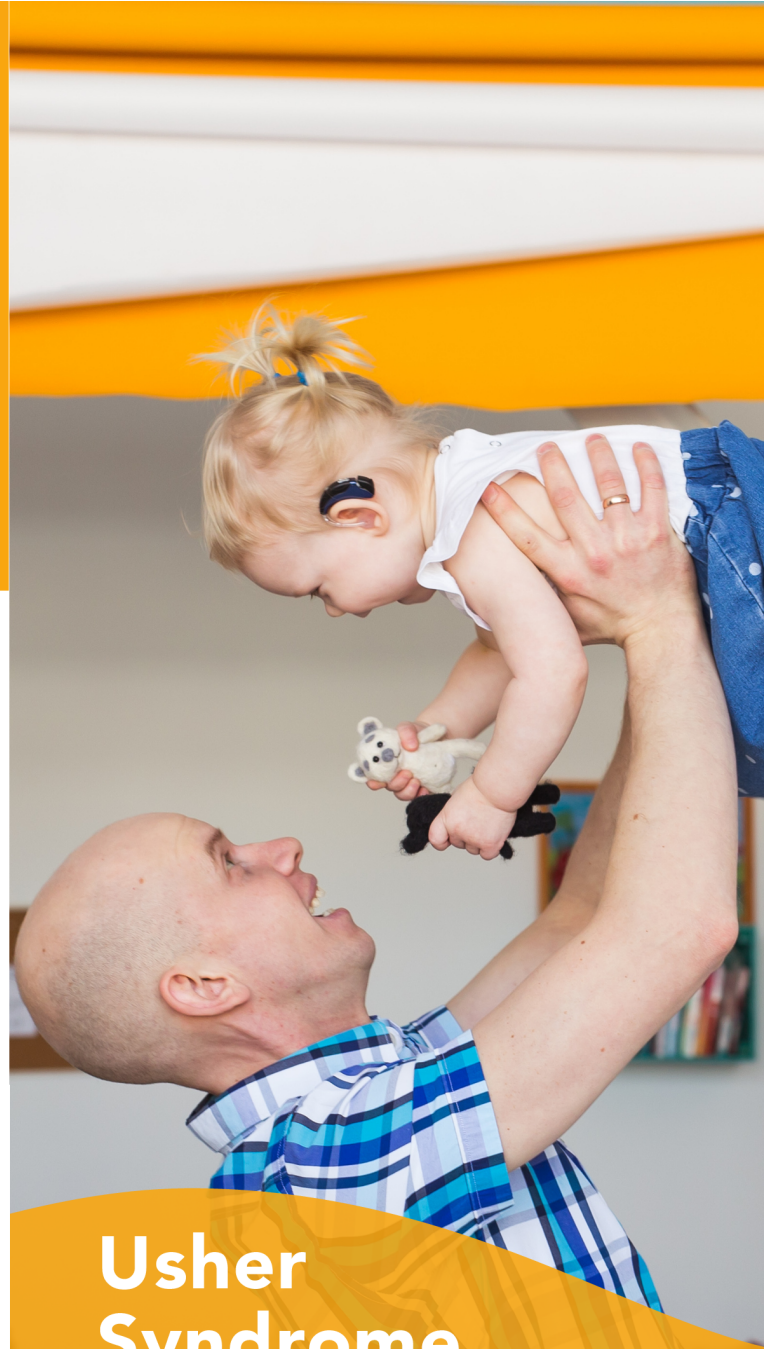
“Together we can support, advocate, and bring hope for a cure.

Usher Syndrome Ireland

Usher Syndrome Ireland is a registered charity, number: 20206288
CRN: 688621

ARE YOU USHER AWARE? #LearnAboutUSH

RARE is... by AMGEN



Usher Syndrome

Information for Patients & Families

WHAT IS USHER SYNDROME?

Usher syndrome, also known as USH, is a rare genetic condition that causes hearing loss and a slow, progressive loss of sight. Some individuals with Usher syndrome may also experience balance issues too.

There are currently three confirmed types of Usher syndrome, with a newly identified type four.

The condition is inherited when both parents pass the same defective USH gene to their child.

To learn more about Usher syndrome, please visit:
www.usherireland.org

Retinitis pigmentosa (RP), a symptom of Usher syndrome, is a progressive condition that leads to night blindness and tunnel vision. This eye disorder affects the light-sensitive cells lining the retina, resulting in gradual vision impairment.

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 living in Ireland with this condition.

LIVING WITH USHER SYNDROME

Usher syndrome affects each person differently, even among those with the same type of USH. This variability can make it challenging for professionals to predict specific aspects of the condition, such as the timing of sight loss onset, the rate of progression, potential worsening of hearing loss, and the extent of possible sensory impairments by a certain age.

Therefore, it's important to maintain regular appointments with your ophthalmologist and audiologist to monitor any changes in both vision and hearing. With the right support and resources, people with Usher syndrome can lead fulfilling and rewarding lives, just like their peers.

We are a patient-led, volunteer organisation established in 2021 to:

1. Provide information & support to diagnosed individuals & their families.
2. Advocate for & raise awareness of USH.
3. Fundraise to support USH research.