

What is Usher Syndrome?

Usher syndrome is a genetic condition which results in deafness or hearing loss from birth and a progressive vision loss. Vision loss often begins in late childhood and is caused by Retinitis Pigmentosa (RP).

What is Retinitis Pigmentosa, RP?

The retina is the light sensitive tissue at the back of the eye in which the first stages of 'seeing' takes place. With RP the retina slowly degenerates and loses the ability to transmit pictures to the brain.



Usher Syndrome Support Group

The Usher Syndrome Support Group was established by Senses Australia in 2007 to provide support for people who have Usher syndrome, their families, carers and friends. The group meets regularly to provide information, education and recreation opportunities, and also to establish fun, supportive social networks for people with Usher syndrome.

Group activities have included:

- Water-skiing/ Canoeing
- Bushwalking/Rock Climbing
- Educational Workshops
- Archery
- Group therapy
- Dinners/ Social Networking
- Deafblind Camp

To find out more or to support the Usher Syndrome Support Group

Contact: Karen Wickham

Social Worker / Deafblind Consultant

Phone: (08) 9473 5462

Mobile: 0424 900 788

Karen.wickham@senses.org.au



Genetics

Usher Syndrome is a genetic condition involving sensorineural hearing loss and retinitis pigmentosa (RP). Although considered a rare disease, it is the most frequent cause of deaf-blindness in humans. It is passed from parent to child in an autosomal recessive manner. This means that a child must inherit one defective gene from each parent in order to develop Usher syndrome. Often parents are unaware that they are carriers until their child is diagnosed with the condition. If a child inherits one defective gene, they will be a carrier and will not have any symptoms if Usher syndrome.

What are the main types of Usher Syndrome?

Usher Type 1: Causes profound deafness from birth, and poor balance. RP is usually recognised before age 10. People generally use Auslan and see themselves as part of the Deaf community.

Usher Type 2: Causes partial to severe hearing loss, RP generally not apparent until adolescence. Speech is the main form of communication.

Usher Type 3: Is rarer and has been specifically recognised in Finland. Normal hearing from birth, and RP develops in adolescence along with hearing loss.



Senses Australia provides a range of services for people with disabilities including unique services for people who are deafblind.

- Early Childhood/School Age Therapy Services
- Deafblind Consultation Service
- Orientation & Mobility training
- Adult Therapy Services
- Accommodation Services
- Alternatives to Employment
- Recreation Services
- Age-Related Dual Sensory Loss Services
- Respite and Family Support
- Sibling Support
- Usher Syndrome Support

For more information

Contact: Senses Australia

Phone: (08) 9473 5400

Fax: (08) 9473 5499

PO Box 143, Burswood WA 6100

Head Office: 11 Kitchener Avenue,

Burswood WA 6100

www.senses.org.au

This information is available in alternative formats on request



Ending the isolation

USHER SYNDROME SUPPORT GROUP



Enabling Enriching Empowering