



Aniridia Network

Aniridia

- Aniridia is a genetic condition that affects the eyes, but can have other effects too.
- People with aniridia have all or part of their irises (the coloured rings in the eyes) missing. It also causes other parts of the eye to not develop fully.
- People with aniridia are either visually impaired or blind.
- A lack of iris to close and shut out light causes people with aniridia to have difficulty seeing in bright conditions.
- 83% of people with aniridia have nystagmus - involuntary eye movements, which reduce vision.
- Aniridia itself will not cause a person's vision to deteriorate over time.
 - It does make you more likely to get conditions such as cataracts and glaucoma which cause sight loss. These are treatable with varying success but they are more complicated for people with aniridia.
- Aniridia is either inherited from a parent who has it, or can occur sporadically at conception
- A person who has aniridia has a 50% chance of passing it on to any child (unless they use PGD).
- Preimplantation genetic diagnosis (PGD) of aniridia is permitted in the UK. It involves in vitro fertilisation (IVF).
- Aniridia occurs sporadically in 1 in 47,000 babies making it a very rare condition
- Approximately 1,400 people in the UK have aniridia.

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Associated conditions and treatments

There are treatments for many of the conditions that people with aniridia may also have, as listed below. However surgery is often more complicated and riskier than normal because of the underdeveloped state of the eye.

- **Nystagmus**, wobbly eyes, cannot be treated. It doesn't cause wobbly vision but makes it hard to focus on things.
- **Cataracts**, areas of clouding in the lens, can be removed with surgery and an artificial lens put in its place. The opportunity can be taken to add an artificial fixed iris to reduce the amount of light that enters the eye though some doctors feel the benefits do not justify the extra risk.
- **Glaucoma** is high pressure inside the eye, treatable with regular eye drops and if necessary with surgery.
- **Keratoconjunctivitis sicca (KCS) or Dry Eye**, is a feeling of burning or gritty eyes, due to issues with the eye's tear film. There are various causes and treatments.
- **Aniridia Related Keratopathy**, clouding of the cornea. It can be treated for a few years with surgery to provide a new cornea and/or Limbal stem cells. Research is ongoing into to the latter.
- **Macular/Foveal Hypoplasia**, is an under-developed part of the retina that sees details, It cannot be repaired.
- **Strabismus** or squint is where the patient cannot align the eyes. Infants can be treated with prescription glasses or a patch to make the weaker eye exercise more or surgery.
- **Stereoblindness** is an inability to see in 3D, i.e. judge depth, distance, direction and speed. It cannot be treated.
- **Ptosis**, a drooping eye lid, It can be treated with surgery or propped up with glasses.

- **Aniridic fibrosis syndrome**, complications that may occur after having an implant in the eye
- **Central auditory processing disorder** is difficulty comprehending what is heard. It may be addressed in a variety of ways depending on the patient.
- **Diabetes and obesity** in connection with aniridia is currently being researched but standard treatments would likely apply.
- **Sleep problems** may be due to abnormality or absence of the pineal gland. These may be treated by taking the drug melatonin but it has to be prescribed off-license.
- **WAGR/11 deletion syndrome** is a more serious genetic condition that a fraction of people with sporadic aniridia also have. The International WAGR Syndrome Association (wagr.org) exists to support these very rare and complex cases.