

The Thalidomide Trust



Why does my patient with Thalidomide Embryopathy experience eye related problems?

Although the most common disability caused by thalidomide is limb difference, a significant proportion of thalidomide affected individuals have damage to their eyes and ears and facial damage.

Data from the Thalidomide Trust's ongoing Holistic Needs Assessments suggest that nearly half of their beneficiaries had concerns over deteriorating eye sight or eye problems. This may reflect both natural ageing and thalidomide-related defects.

Anatomy

Thalidomide affected individuals may display some of the following anatomical features¹:

- Coloboma of the iris +/-coloboma of the retina
- Under-development of the globe leading to anophthalmos or microphthalmos
- Poor visual acuity
- Defects of eye movements-the commonest being that abduction of the eye is reduced or missing. In more severe cases, abduction and adduction are equally affected, causing tunnel like vision
- Abnormalities in tear-duct formation
- Facial palsy

Specific issues to consider

For those with upper limb dysplasia, adjusting/ changing glasses can be difficult or impossible without assistance.

Equally, for those with microtia or anotia, it may not be possible to wear glasses.

What can I do for my patient with eye problems?

As balance and recurrent falls are common within the thalidomide community, early detection of worsening sight issues is crucial so recommending regular optician review is advised, together with an early referral to Ophthalmology, if appropriate.

Optician reviews may also pick up signs of hypertensive disease, which may be useful if blood pressure is difficult to measure in a particular individual.

Consider the need for lens replacement/laser surgery if putting on/taking off and adjusting glasses are problematic due to upper limb dysplasia and/or microtia/anotia.

Here is a Trust case study on how laser eye surgery was transformative for a thalidomide affected individual:

<https://www.thalidomidetrust.org/laser-eye-surgery/>

How can the Thalidomide Trust help?

The Thalidomide Trust can write a supporting letter if funding is required from the CCG for referral for lens or laser surgery.

The Thalidomide Trust also has some information on laser eye surgery on its website that you can direct thalidomide affected individuals to:

<https://www.thalidomidetrust.org/health-and-wellbeing/health/laser-eye-surgery/>

The **Thalidomide** Trust

If a beneficiary needs referral to secondary care for assessment and you are facing prolonged NHS waiting lists and/or the need is urgent, the Thalidomide Trust can assist in making a private referral which can generally be funded from the individual's Health Grant (specific funding allocated to each thalidomide affected individual to cover additional costs associated with their thalidomide disabilities).

Whether you would like general advice or would like to discuss a specific patient, you can speak to one of the **Thalidomide Trust's Medical Advisers** on **01480 474074**.

