



DUAL SENSORY MANUSCRIPT PLAIN LANGUAGE SUMMARY

What is Norrie Disease?

Norrie Disease is a rare, inherited condition that affects mostly males. People with Norrie Disease are usually born blind or become blind during early childhood. They may lose their hearing as they grow older, and develop other symptoms. Hearing loss worsens into adulthood and most patients will need hearing aids. Children with Norrie Disease often enjoy activities using sounds and music, which makes hearing loss distressing. Difficulties include interacting with friends and family and continuing with hobbies. Being able to live an independent life may be challenging.

What Challenges do Patients Experience?

Children with Norrie Disease need regular monitoring of their eyes and ears. Patients may need to see multiple doctors in different clinics and hospitals. These appointments can be stressful and disruptive to their school attendance. Travelling to clinics can be expensive for parents and carers, particularly if time off work and childcare are required.

How Can Dual Sensory Clinics Help Patients with Norrie Disease?

Dual Sensory clinics have been suggested for children with Norrie Disease and their carers. These clinics bring together doctors specialising in hearing, vision and other senses, who have experience with rare conditions like Norrie Disease. Children with Norrie Disease can see all of these specialists on the same day. This reduces travel time, costs and time away from school. Dual Sensory clinics are designed for children with sensory problems and the environment is adapted to make it relaxing and accessible for patients. Regular hearing tests ensure that hearing aids are reviewed and updated, to reduce the day-to-day impact of hearing loss. Patients also have access to a variety of other specialists if required.
