

In developed economies, premature birth is the commonest cause of acquired blindness in childhood.

Retinopathy of prematurity (ROP) is the most common treatable cause. It is an ischaemic retinopathy. The burden of blindness to individuals, families and society is lifelong.

The retina can be thought of as visible grey matter and the disease visible in the eye often mirrors that unseen in the rest of the brain.

Cryotherapy treatment of the ischaemic retina in ROP was first shown to help in the 1970s. Subsequent landmark trials have shown significant reduction in blindness with laser ablation and most recently with non-destructive treatments including intravitreal injection of anti-vascular endothelial growth factor (VEGF) agents and topical steroids. The long-term effects of these newer treatments are unknown.

Disease registries generate real world data that complement trial-based research and inform the path ahead in clinical treatment and research.

Sydney University and Save Sight Institute's suite of registries has, as its most recent addition, the Fight Retinal Blindness (FRB!) ROP registry.

Treated retinopathy cases are being added to this registry across Australia, New Zealand and other countries in the region.

Developmental input from neonatologists and developmental paediatricians will be an invaluable part of this clinical research.