

The Nuts and Bolts of Patient Registries

A National Register for Inherited Retinopathies



About the Registry!

- Estimated 5000 individuals with an inherited retinal degeneration (IRD).
- Clinically-led, interoperable database accessed across 3 registry sites.
- Based on models used in Germany and The Netherlands, centres of expertise.
- Cases uploaded by clinicians using an electronic case report form (CRF) which includes information:
 - ✓ full clinical assessment
 - ✓ family history
 - ✓ technical examinations
 - ✓ genetic information

Stage of Development

- Consent process finalised across all three sites allowing transfer of data onto register.
- Fighting Blindness fund Clinical Fellows at clinics to assist with clinical assessment and uploading information.
- Continuously updated as new patients identified and recruited or called back – **Natural History**.
- Close to **1,500 people recruited** to Target 5000.
- Support for database runs out in 2018

Get In Touch



[Facebook.com/FightingBlindnessIreland](https://www.facebook.com/FightingBlindnessIreland)



[@fightngblindnes](https://twitter.com/fightngblindnes)



[instagram.com/fightingblindness](https://www.instagram.com/fightingblindness)

W: www.FightingBlindness.ie

E: research@fightingblindness.ie

T: +353 1 6789 004