ERN on eye diseases (ERN-EYE)

Rare Eye Diseases (REDs) are the leading cause of visual impairment and blindness for children and young adults in Europe. More than 900 REDs are listed in the portal for rare diseases and orphan drugs (ORPHANET), including more prevalent diseases such as retinitis pigmentosa - which has an estimated prevalence of 1 in 5,000 - as well as some very rare conditions described only once or twice in medical literature.

In close collaboration with ePAGs, ERN-EYE addresses these diseases in four thematic groups: rare diseases of the retina; neuro-ophthalmology rare diseases; paediatric ophthalmology rare diseases; and rare anterior segment conditions. In addition, six transversal working groups are addressing issues common to the four main themes. Additional working groups focus on specific areas, including genetic testing, registries, research, education, communication, low vision and patients groups, and national integration.

One of the most important ERN tools is the CPMS, a virtual clinic IT platform with a dataset dedicated to REDs. ERN-EYE focuses on improving patients' diagnosis and care across the EU through connecting and enforcing expert networking; knowledge and information exchange; development of educational and training programmes such as webinars or e-Learning program); creation of a European interoperable registry (REDdistry); and development of guidelines and good practices documents.

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